Steve Hewlett's Journey with Advanced Oesophageal Cancer: A Case Study

A thesis submitted in partial fulfilment for the degree of Doctor of Philosophy (PhD) in Social Science.

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Abstract

Oesophageal cancer (OC) is typically diagnosed at the later stages of the disease due to its vague symptoms. Over 9000 people in the UK are annually diagnosed with the cancer and the survival rate is only 12% (Cancer Research UK, 2013-2017), therefore it is vital that people are diagnosed at the earlier stages of the disease for increased chances of survival. OC has been an under-represented cancer in the media for raising public awareness of symptoms when compared other cancers such as breast or prostate.

In March 2016, Steve Hewlett, a British journalist and broadcaster, was diagnosed with late-stage OC at the age of 58. Shortly after learning of his diagnosis, he made the decision to share his cancer journey with listeners on BBC Radio 4 (the PM Show). A total of 21 interviews took place on air with radio presenter Eddie Mair. Steve also released dairy entries, as well as taking part in other media interviews. A range of guests were invited to speak on the PM Show including: family members, health professionals and the occasional listeners who phoned in to express their interest and appreciation for Steve's reporting.

The aim of this research was to examine Steve Hewlett's cancer journey (pre-diagnosis to end-of-life stages) as depicted in the media, with the exploration of techniques used to share health information and personal experiences with his audiences. This provided a unique and in-depth perspective of OC as a journey.

Case study (CS) methodology was used which encompassed the use of multiple sources such as radio interviews, television interviews, newspaper and diary entries. These were supported by the validation technique of triangulation to check for consistencies in reporting experiences and perceptions throughout the different contexts and reporting mediums. All data was pre-existing (ranging from 2016-2017) and publicly available on the internet. Audio and video interviews were transcribed verbatim and analysed with thematic analysis, underpinned by an interpretivist researcher stance.

Five main themes were developed that chronologically mirrored the journey: Unexpected Diagnosis: *My luck's run out*; The Active Patient: *On the phone to the drug manufacturers*; Buying Time with a Lucky Break; and Death and Dying: *I could pop off at any time*. Findings showed that Steve's communication to listeners had multiple purposes. Purposes included: teaching the public about OC signs and symptoms (raising awareness), explaining NHS referral and treatment processes (how to get the best care possible), sharing experiences and the options available in private treatment and, costs associated with this and lastly, breaking social barriers for men's health and identity when diagnosed with cancer. In addition to factual reporting and personal narrative, metaphor was also used to enhance health communication.

The combination of personal and journalistic stories about OC showed the various and creative ways of Steve's reporting. These included metaphors, health frames and narratives that may be available to audiences when interacting with journalist cancer stories to make sense of certain cancer experiences and the healthcare system. The combination of personal and journalistic reporting about OC showed the multiple methods of Steve's reporting, which included modelling and potentially showing ways to take responsibility for one's own health such as enquiring about delayed referrals; demonstrating shared decision-making process; coping and navigating one's self through the journey using helpful information sources, ultimately exemplifying a way of becoming an informed and potentially 'expert' patient. To fully understand audience perceptions of the impact or usefulness of journalist cancer stories, further research is required.

Dedication

This thesis is dedicated to all journalists and writers who have selflessly shared their personal cancer journeys to raise awareness to help others detect their disease earlier, so that they may live. This case study is just one example of the many important works that journalists do to create positive and essential impact upon public health.

And also, for my nani (grandmother), Krishna Soni, who passed away from throat cancer when I was a year old. I wish you had known the signs and symptoms earlier so that we could have had more time together. Your love is always with me.

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"what if
there isn't enough time
to give her what she deserves
do you think
if i begged the sky hard enough
my mother's soul would
return to me as my daughter
so i can give her
the comfort she gave me
my whole life"
-**The Sun and Her Flowers**

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Abbreviations

A1 - Anonymous 1

A2 - Anonymous 2

A3 - Anonymous 3

C.E - Chief Executive

CS - Case study

E - Eddie (Mair)

Int. - Interview

Int. RB - Interview with Roger Bolton

Int. VD - Interview with Victoria Derbyshire

MN - Macmillan Nurse

NICE - National Institute for Health and Care Excellence

O – Oncologist

OC - Oesophageal cancer

RB - Roger Bolton

RTM - Radio Times Magazine

S - Steve (Hewlett)

Su - Surgeon

VD - Victoria Derbyshire

Chapter One: Introduction

1.1 Introduction

Raising health awareness among the general public is an important activity for many reasons. It can help to prevent future disease, educate people and create interest and dialogue between and amongst the public and health institutions to promote health and well-being. The way that health awareness is raised is flexible and there are many methods and outlets to reach people to be able to pass on important health messages. This includes social media, digital and print media, word-of-mouth, self-education through websites and health literature and, novel personal experience. Within the context of cancer, a key aspect of raising health awareness concerns the identification of symptoms that indicate the presence of the disease. Being aware of cancer symptoms at an early stage of the cancer or as soon as these present, means that more treatment options are available, therefore increasing the survival rate for the individual.

Within the media, the reporting of personal cancer stories and journeys by journalists are becoming more common, helping to raise awareness, creating dialogue and expose the harsh and unseen reality of dealing with the effects and treatment of cancer. This PhD research focused upon the longitudinally-reported experience of dealing with oesophageal cancer (OC) by journalist and radio broadcaster Steve Hewlett. OC has been regarded as a silent disease with vague symptoms (Layke & Lopez, 2006) that can often be mistaken for general, everyday symptoms, such as indigestion or acid reflux. OC is not as widely reported in the news and media as some other more common cancers such as lung or breast cancer. However, the topic was extensively reported upon on by Steve in his journey between 2016 and early 2017. This this PhD research is based upon a single case study (CS) of Steve's reporting, health and policy investigations, experiences, perception and conclusions about dealing with OC: from the pre-diagnosis stages up until end-of-life.

Within this introductory chapter, I will cover background and history of journalists reporting on health in the media with examples and discuss typical methods of raising cancer awareness. In particular, a discussion is provided on awareness-raising methods implemented by the UK government within recent years through the help of the media. This is then followed by an outline of the 'case', which entails Steve's journey with cancer and sharing this through multiple media outlets. Leading on from this, I provide further rationale for this CS research with the research question and objectives of the study. Further context to OC including epidemiology and current issues relating to diagnosis to treatment are also discussed to provide a foundation for the reader, before moving onto the literature review (chapter 2). Lastly, I will share my background and experiences in healthcare which have influenced my interest to study OC and Steve Hewlett's story. A brief summary to concludes this chapter.

1.2 Cancer awareness and reporting in the media

There are various reasons why journalists report upon health stories and this is dependent upon the motive behind the information or story shared. Motives usually consist of bringing current developments in health news, such as treatment advances or cancer research, to the attention of audiences (Dorfman & Krasnow, 2014). A common motive of health news is to raise awareness about diseases and educate the public, even if on a shallow level, about a current health issue, quality of life and early mortality. In more recent years, a product of the health-awareness movement in the media has been that of personalised stories of journalists and broadcasters, bringing a different perspective of health, coping and illness experience to audiences. Personal stories, such as cancer journeys have been documented through biographies, memoirs and newspaper columns by writers. These have shed light on living with the disease from each of their unique perceptions, world views, treatment experience and changes that have occurred as a result of adjusting to cancer. Some examples include works by writers and journalists, John Diamond (1998), Ruth Picardie (1998), AA Gill (2016), Nina Riggs (2017), Anne Boyer (2019).

Sharing personal health experiences and anecdotes has been adopted by journalists and used as a method to report and raise awareness about cancer, delayed diagnosis, screening, recognising symptoms and ways to seek help and healthcare. Some more recent journalist stories have included a journalist's own illness, recovery and end-of-life stories (Victoria Derbyshire 2015, Ali Meyer, 2018, Nick Robinson, 2015, Alexandria Glorioso, 2019, Bill Turnbull, 2019, George Alagiah, 2019, Jeremey Bowen, 2019, Kristen Dahlgren, 2019), each of which have covered different aspects of the cancer journey, which reflects that not everyone's road to recovery or initial diagnosis experience is the same. Various journalist reporting shows the different challenges that arise with cancer, demonstrating that access to healthcare, level of vigilance, levels of prior knowledge of cancer symptoms, play an important part in the early diagnosis and chances of survival.

Noteworthy recent examples discussed below (1.2.1), show the unique situation that each journalist encountered when diagnosed with cancer, undergoing treatment and dealing with the physical and psychosocial effects of cancer. Thus, this type of personal health reporting by journalists aimed to create health awareness by providing a range of new stories, new topics and perspectives to discuss, even when the basic theme of a cancer story remains the same across stories.

1.2.1 Journalist cancer stories in the media

Victoria Derbyshire (2015)

In September 2015, journalist and broadcaster, Victoria Derbyshire began to document her breast cancer journey in the form of a video diary with a total of 6 episodes (aired on the BBC). Within these episodes were multiple diary entries presented chronologically, covering aspects of the journey such

as the mastectomy, chemotherapy, hair-loss prevention treatment, radiotherapy, and the final treatment appointment. In a later video, Victoria revealed that her hair had grown back after removing her wig, showing the success of treatment and survival after months of dedication to treatment. In 2018, she was contacted by members of the public who were diagnosed with breast cancer, shortly after having sought medical help as a result of remembering the signs and symptoms that Victoria had reported on her programme. As a result, these video diaries proved to be impactful in raising awareness about breast cancer but also exposing the harsh reality of dealing with cancer, useful to those unfamiliar to the experience of cancer.

Ali Meyer (2018)

A similar personal story in breast cancer was shared by Ali Meyer, a reporter for Oklahoma's News 4 channel. During breast cancer awareness month in 2018, she decided to produce a story where she would walk her audiences through the procedure of undergoing a mammogram from start to finish. This was conducted on Facebook Live so that audiences would share her journey as it happened, learn about the types of healthcare professionals that a person would expect to meet at the appointment and the type of environment that the scan takes place in. This was all done to motivate others to take up their scheduled mammogram appointments and educate those who have not had one before so that they could then become aware of the of how easy, unpainful and harmless the procedure is. The live reporting on Facebook Live took a turn when the radiologist found a questionable lump in her breast which required further investigation. During the live report, Meyer shared this information with her audiences after being told this and audiences were exposed to the confusion and anxiety that she experienced during that uncertain time.

Ali then decided to update her audiences on Facebook Live once again about an upcoming MRI scan and genetic testing that she had to identify if she had the genetic mutations for breast cancer. After this, she was scheduled for surgery and voiced her feelings of sadness and concerns about losing the most 'intimate part of her body'. Using her own doctors and plastic surgeons that had treated her, she held interviews with them where she described her worries, which were addressed by the professionals. These interviews drew upon Ali's own health and cancer, which were used as examples by the doctors to explain how they respond to and advise patients during a difficult and sensitive times. A significant interview she conducted was with her plastic surgeon who de-clouded the fear surrounding losing the whole breast surgically as a result of the cancer. Using Ali's personal example once again, the surgeon described that it is possible to leave skin tissue and the areola as to not to lose the whole breast in the process of reconstruction.

Ali ended her journey by reminding her viewers of the brilliance of the mammogram that was able to show the presence of the cancer even before she knew, suspected or had even experienced any signs and symptoms. Thus, leaving the powerful message to audiences of the importance of routine mammograms, which can bring to light unexpected and asymptomatic early cancers. This message was reinforced a year later when Ali received the 'all clear' at her second mammogram during breast cancer awareness month, showing the full circle of living, diagnosis, treatment and back to living after a successful journey.

Kristen Dahlgreen (2019)

In December 2019, NBC journalist Kristen Dahlgren shared how she recognised the signs of her breast cancer, after having reported on the very same symptoms in a 2016 public health story with the help of an oncologist. The 2016 story was produced to raise awareness about the types of symptoms one would encounter, with an aim to help audiences recognising vital signs which could save lives. After noticing that she was experiencing the same symptoms that she had reported upon previously, she immediately sought a mammogram and was diagnosed with stage two breast cancer.

Although she generally considers herself a 'private' person, she decided to share her cancer journey with audiences in her latest 2019 report, due to the irony of her previous journalistic work in saving her own life a few years later. After being treated with chemotherapy, Kristen was adamant to share her story to remind others about cancer signs, with the additional message of attending breast screening; something which she admitted to having avoided in the past. With this example, it was seen that health reporting can act as a reference points for people when interpreting certain symptoms as well as raising awareness about symptoms. This case showed the importance of being aware of potential cancer symptoms, where audiences were provided with context, which was Kristen's personal journey of recognising, acting upon and seeking help for symptoms and the underlying cancer. As such, the same message from the 2016 report was reinforced to audiences with the context of a real-life breast cancer story that happened to be the story of the journalist herself.

Alexandra Glorioso (2019)

Other journalists have reported on different aspects of dealing with cancer other than diagnosis and screening. Within the written digital media, another self-reported cancer story was by health reporter Alexandra Glorioso who wrote an extensive essay in November 2019 for Politico Magazine detailing her drug treatment protocol, surgeries and clinical challenges in breast cancer. Clinical challenges also overlapped into the personal aspects of dealing with the cancer's effects. One example related to her relationship with her then boyfriend (now fiancé) and potential issues that pregnancy would bring in the treatment of cancer and in advancing the growth of cancer. Inducing early menopause and future

egg freezing was a topic discussed within the essay. This showed the breadth of the implications that breast cancer can have upon a woman looking to plan a family.

The cancer journey was reported candidly, exposing the medical difficulties, emotional and mental impact of the disease. These written experiences were supplemented by photographs of treatment, surgery scars and emotionally-intimate moments between Alexandra and her fiancé. She brought to audience's attention that being a knowledgeable health reporter had in no way prepared her to be able to cope with cancer. This demonstrated that a factual knowledgebase alone is not sufficient information in helping a person to understand the effects of cancer and generally within the efforts of raising cancer awareness. Context, in the form of real-life examples creates the potential to understand the different ways that cancer causes issues and obstacles in various aspects of life (social, physical health, personal relationships), as well as showing how early symptom recognition or experience can affect the trajectory of the cancer.

Nick Robinson (2015, 2018)

Journalist and BBC radio presenter, Nick Robinson reported on his lung cancer in 2015 and then again later about the mishaps that can occur from cancer treatment. He shared the complication that he had occurred during the removal of the tumour from his lung that left him with damage to his vocal cords. This had left him unable to speak as he did before and had to have speech therapy to restore his voice. This story showed the indirect effects of the cancer, such as issues that can occur from trying to cure or remove it, demonstrating that treatments hold risk too.

Jeremey Bowen (2019)

Similar to Ali Meyer, a brief health awareness message was delivered by journalist Jeremey Bowen to attend bowel screening tests after being diagnosed with bowel cancer himself. Here, he advocated for people to not 'die of embarrassment' due to the potentially embarrassing symptoms and intimate check-up during investigation of the cancer. In a later 2019 BBC article, he admitted that he had not experienced any symptoms of the cancer. He had only experienced pain in his legs and in his back, at which doctors believed the pain to be from scarring from previous surgery. Although he did not experience the classic signs of bowel cancer, this evidenced the silent nature of the disease and atypical presentation of signs. As a result, he felt that individuals ought to be vigilant about abnormal bodily changes and go with their instinct, as Jeremy did when he decided to opt for a bowel screen even with the lack of presence of bowel symptoms.

Bill Turnbull (2019)

Journalist Bill Turnbull was diagnosed with prostate cancer in 2018 and made a documentary about his cancer journey with Channel 4, documenting the raw and intimate and emotional experiences that

he had when trying to find a suitable treatment for the cancer and his pain. Topics such as treating pain with cannabis were discussed and shown to audiences, exposing the different measures that those with cancer try in order manage the pain. Bill is now an ambassador for Prostate Cancer UK and has said that the aim of his 2019 documentary of his personal cancer journey was to "paint a picture of what it's like to live with prostate cancer, to show how it feels to ride the Big C rollercoaster." Another aim of the documentary was to enable audiences to learn about prostate cancer and raise awareness about screening and diagnosis (Prostate Cancer UK, 2019).

George Alagiah (2019a, 2019b, 2020)

George Alagiah, a journalist and BBC news presenter, was diagnosed with bowel cancer in 2014 which had returned in 2017 at stage four of the disease for which he restarted treatment. Initially, this was not reported by George, however, in late 2019 he held six interview podcasts with people with bowel cancer along with medical professionals, psychologists and the chief executive of the charity Bowel Cancer UK. These included discussions on treating the disease, emotional wellbeing, caring for a loved one with cancer, managing a stoma and generally coping and living with the disease. These podcasts were created in conjunction with Bowel Cancer UK and aimed to raise awareness and de-mystify the vast amount of information surround bowel cancer through different sources of knowledge, but also how to improve quality of life.

In March 2020, George was interviewed remotely in his home by a fellow BBC colleague during the Covid-19 pandemic, where he shared that he had contracted coronavirus with minor symptoms such as a temperature. He had a message for those with cancer who may be worried or anxious about the getting the virus. The message was to reinforce that those with cancer are familiar with uncertainty and a life-threatening situation, making them stronger than the average person to be able to cope with the virus if contracted. The interview raised awareness about the reality of anxiety that people with cancer would be experiencing during the pandemic but more importantly, reminded them that they were equipped with the physical and psychological experience of their current disease to be able to deal with a mild case of the virus.

1.3 The Case: Steve Hewlett's Journey

The above cancer stories were briefly and less frequently reported in the media by the authors. In comparison, Steve's story was the longest reported cancer journey in the media without a break, with in-depth coverage of each aspect of the cancer journey: pre-diagnosis, diagnosis, treatment, various obstacles and end-of-life treatment.

1.3.1 Journalism and The Media

Steve Hewlett was a journalist and broadcaster who started his career as a freelance researcher for information and facts to be used in journalism stories[1]. See figure 1 for a breakdown of his career history.

Figure 1: Steve Hewlett's List of Journalism and Media Roles[1]

Career History

1994-1997	Editor of Panorama (BBC)
1997-1998	Head of Factual, Progression and Features (Chanel 4)
1998-2003	Director of Programmes and MD Productions (Carlton TV)
1998-2004	Director of Programmes/Production (ITV/ Carlton TV)
2004-2007	Non-Executive Director (Tiger Aspect Productions)
2003-2017	Fellow, Royal Television Society

Additional
Visiting Professor of Journalism and Broadcasting Policy (University of Salford)

In 1989, he worked as Editor of Inside Story, creating content such as The Maze prison documentary which explored a high security prison in Northern Ireland. Shortly after, he received a consumer journalism contract at the BBC but swiftly moved to Channel 4. By the mid 1990's, Steve became Editor of Panorama where he and his team centred on 'hard-hitting' and captivating investigative journalism[1], with arguably the most famous story being the interview episode with Princess Diana, where Martin Bashir uncovered the conflict in her marriage with Prince Charles. The famous and unforgettable line spoken by Diana, "there were three of us in this marriage", was one of the many exposés that let audiences into the Royal Family's domestic issues, creating the potential to *bring down the BBC and its executives*[1]. Despite the risk of airing the interview, it was still shown and successfully gained an audience of 23 million on the night[2].

During the course of his Panorama and journalism career, Steve worked on and developed 20 'big stories' on serious politically and socially-relevant topics, which included the smuggling of plutonium out of Russia to sell in London; the sale of second-hand cancer-causing x-ray machines; an interview with Colonel Gadaffi and further exposing Saddam Hussain's chemical weapons facility[2]. As described by his colleagues at the BBC[2], Steve had a 'social conscience' and his inclination towards demonstrating facts and unbiased journalism was guided by this and interest in exposing serious issues; some of which included discussing the abuse of vulnerable people in care and the illegal sale

[1] Views or facts shared by various BBC colleagues on The Media Show Tribute to Steve Hewlett (Radio 4, February 2017).
[2] As stated in The Media Show Tribute to Steve Hewlett (Radio 4, February 2017).

of alcohol and drugs to children. In exposing such stories, he brought to light the other (hidden or untold) side of the story, which provided the complete story to his audience. Director of the BBC, Tony Hall, called him a 'trusted voice in public service journalism' and colleagues regarded him as being a storyteller who was curious and critical about situations and relied on simply the research and the facts to uphold his stories[2].

After his role as an Executive at Carlton and Chanel 4, Steve was made redundant, however his critical and analytical abilities paved the way for him as a media commentator. His journalistic rigour and curiosity to uncover facts and truths in situations became extremely relevant professional attributes in discussing and questioning current affairs in the media[2]. In 2005, he had his own column in The Guardian where he proved his understanding of the media through the broadsheet medium. Then in 2008, he founded The Media Show on BBC Radio 4, where once again, critical tenacity, interest for stories and facts, as well as vast -journalism experience added to his positively-received broadcasting[2]. The show was received so well that Steve won the Nick Clarke award for his journalism in 2011 (BBC, 2011).

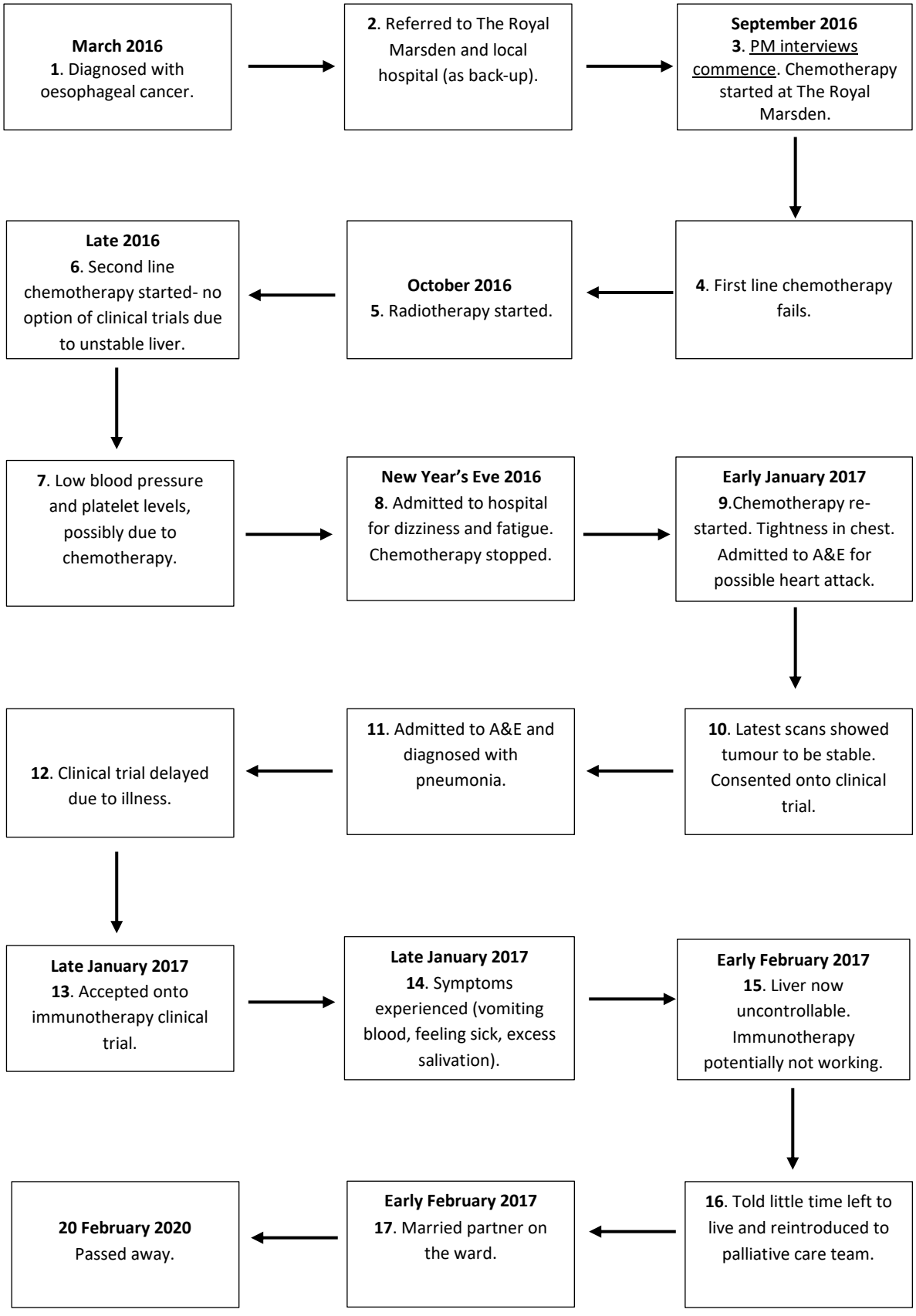
Gwyneth Williams, previous Controller of Radio 4 described Steve as a *rational* and *informed* journalist, and other colleagues knew him as an *encyclopaedia of media knowledge*, who could always provide context and meaning to stories thus flawlessly answering the question, *what is the point of this* (story)*?*[2]. In addition to his practical skills and knowledge as a journalist, he was seen to be a good at establishing relationships through relating to people in the research processes of producing a story; a *people's person* who could extract information from various people and sources by simply *being himself'*[1]. Toward the end of his life, during his reporting of his cancer, his colleagues recognised the same use of his journalistic and story-telling skills[1].

1.3.2 Cancer Diagnosis and Reporting

In March 2016, Steve was diagnosed with OC and made the decision to document his life with cancer (The Guardian, March 2017). He then reported his cancer journey with radio host, Eddie Mair on the PM show on Radio 4, detailing his experiences, progress in cancer treatment, and decision-making related to his health and personal life. Overall, he took part in over 20 interviews on the PM show and wrote multiple newspaper columns about his cancer journey to update and inform his audiences of the trajectory of his health. The nature of these interviews was candid and untypical of BBC broadcasting material, but illumined the unexpected experiences and obstacles associated with advanced-stage OC. Reporting of his cancer was done over the span of 6 months (September 2016 to

February 2017). Figure 2 shows a timeline of the key events that took place during Steve's cancer journey. An In-depth break-down of each PM show interview is provided in chapter 4 (4.3.1).

Figure 2: Timeline of Events in the Cancer Journey



1.4 Rationale for this study

With the use of the digital media and innovate and modern ways of sharing information such as video diaries and live streaming of procedures, there are increasingly more journalists using their skills to explore their own cancer journey. These can be sensitive experiences to share. However, those willing to blur the boundaries of professional and personal storytelling, can help to deliver invaluable benefits to audiences who follow and learn about health from these types of stories. There are a range of ways in which information is delivered but there has been scarce social research on how journalists share a vast amount of information, how this is delivered and the techniques employed (e.g. communication, teaching, providing examples, modelling health behaviour), and the possibility to engage and raise awareness among their listeners. Steve's reporting of his cancer story was extensive, reported over a number a digital outlets, reached a large number of audiences and was about OC, an under-reported cancer within the media, known for its vague and often mis-diagnosed symptoms. These factors made Steve's story a compelling and worthwhile journey to explore in social science research. In order to understand these techniques, analysis of Steve's experiences and views is required to contextualise these techniques and understand his journey and the challenging empierce of dealing with OC symptoms and treatment

According to The Aarhus Statement (Weller et al., 2012), research with people with cancer, should be conducted within a reasonable time frame to ensure a great deal of recall bias does not affect research validity. It is however, acknowledged that recall bias is inevitable within any psychological and health-related research involving experiential reporting (Croyle, Sun & Hart, 1997, p.268). Within the context of OC, it is possible for patients to experience symptoms for months to a year before a referral by a GP is made (Jones, Latinovic, Charlton & Gulliford, 2007). Therefore, together with the pre-referral interval and post-diagnosis period in which patients have been interviewed, this added time may affect a person's true reporting of their experiences and would affect reliable researcher analysis. As Steve's experiences with his health were reported within a week of occurring, this would have prevented the impact of memory distortion and or, bias in recall of events. This also contributed to the rationale to specifically explore Steve's experiences as these were reliably documented and reported within a short time-frame, compared to any other recent journalist's reporting of the cancer.

1.5 Research Aim

The aim of this study was to explore how Steve reported his cancer and healthcare journey in the media, which included exploration into how he investigated topics related to OC and its care, and how this was presented to audiences.

Objectives:

- Explore the different ways in which Steve Hewlett raised awareness about OC, the treatment process and coping with the disease (use of facts, science, policies, official documents, other sources in addition to personal experiences).
- Identify the techniques that were used to do this (psychosocial, journalistic, linguistic, description of personal experiences and perceptions).
- Examine how a journalist's reporting of their own cancer story is different to lay reports in the media.

1.6 Oesophageal Cancer

Oesophageal cancer (OC) is cancer of the oesophagus (food pipe); there are two types, adenocarcinoma and squamous cell carcinoma (Ajani et al., 2011). There are four grades of OC, ranging from stage one to stage four. The stage at which a person is diagnosed indicates the size and spread of tumour(s). Each stage has sub-categories that indicate details of the cancer's progression and the location within the body[3] (Rice, Patil & Blackstone, 2017 [American Joint Committee on Cancer], Cancer Research UK, 2017; Tobias, Hochhauser & Souhami, 2010).

Stage one: The cancer is contained within the oesophageal wall which means that it has not spread to other tissue, lymph nodes or organs.

Stage two: The cancer had grown into the outside of the oesophagus or has not protruded into the muscle layer but has spread to a few nearby lymph nodes and nowhere else.

Stage three: The cancer has grown into the tissue surrounding the lungs, heart or muscle near the diaphragm. Or, it has grown to the muscle layer or membrane covering the oesophagus and has spread to three or more lymph nodes. Or, it has grown into nearby areas such as the windpipe, spine, or a major blood vessel as well as spreading to the lymph nodes. Lastly, instead of the above, it has spread to seven or more lymph nodes but not anywhere else in the body.

Stage four: At this stage, the cancer is advanced and has spread to other major organs such as lungs or liver as well as numerous lymph nodes.

OC is an under-researched cancer in comparison to other more frequently diagnosed cancers such as breast and prostate cancer. There has been, and continues to be a need for attention to this area to help understand the important reasons as to why a high percentage (over 50%) of patients world-wide

[3] For the purposes of this thesis, the description of stages has been condensed for concise and overall depiction of the different diagnoses of OC. For further information about the types of OC, see NHS England (2019) or Cancer Research, UK (2020).

are diagnosed at late stages of the disease (Devesa, Blot & Fraumeni, 1998; Macdonald, Macleod, Campbell, Weller & Mitchell, 2006; Short, Burgers & Fry, 2017). Currently, delayed diagnosis cases are attributed to a number of factors, with the main being that this specific cancer often has 'silent' or 'general' symptoms that are not experienced until the cancer (tumour) grows significantly (NHS England, 2019) at which time it blocks the oesophagus and, or begins to amplify symptoms once it has metastasised (Layke & Lopez, 2006). Another factor is that the symptoms can be mistaken for common ailments, such as acid reflux (Enzinger & Mayer, 2003; Humphrys et al., 2020), often perceived to be unharmful and treatable with proton pump inhibitors (Bramble, Suvakovic & Hungin, 2000).

If OC is not detected early enough, it is difficult to treat even with surgery, which often leads to palliative care soon after diagnosis (Layke & Lopez, 2006; Thrumurthy, Chaudry, Thrumurthy & Mughal, 2019).

1.6.1 Epidemiology

OC is the eight most common cancer worldwide (Short et al., 2017) and within the United Kingdom (UK), it is the fourteenth most diagnosed cancer, representing two percent of all cancer diagnoses within the country (National Health Service, NHS, 2013) and five percent of all cancer deaths (Cancer Research UK, 2017). In total, just over 9,000 people are diagnosed with OC annually, with an average of 21 deaths per day and only 12% of people survive the cancer and live for ten years or more (Cancer Research UK, 2017). In 2016, a NHS audit of the oesophago-gastric cancer diagnostic pathway (to hospital care) found that only 23% of patients were diagnosed at any early stage (NHS England, 2019) demonstrating why survival rate and health outcomes are so poor for this patient population.

Typically, patients diagnosed with OC tend to be 70 years and above (Jones, Latinovic, Charlton, & Gulliford, 2007). However within recent years, younger, middle-aged patients (50+) are now being diagnosed with OC (Brown, Devesa & Chow, 2008; Layke & Lopez, 2006). This has been attributed to lifestyle choices such as diet (lack of fruit and vegetable consumption), alcohol use, lack of exercise leading to obesity, smoking and drug usage (Cook et al., 2010; Short et al., 2017).

Compared to previous statistics, OC rates have increased by 43% since the late 1970s, which includes an overall increase for both males than females, but from the years 2002-2013, rates of OC have remained stable (Cancer Research UK, 2013, 2017). However, the stage at which patients are diagnosed at has not changed (stages three and four of the cancer) and this continues to have a detrimental effect on subsequent survival. Therefore, stage of diagnosis still remains a critical issue. Within the UK, a large number of patients are diagnosed with advanced-stage OC, leading to a significantly decreased likelihood of treatment with curative intent (National Oesophago-Gastric Cancer Audit, 2016, 2019).

Looking at the wider context, the latest European statistics show that there has in fact been a decline in mortality rates of OC, in particular, a small decline in male mortality, but this has not been the case within females, which has remained at the same rate over the years between 1980-2011 (Castro et al., 2014). These cases have been seen to reflect the possible decrease in tobacco smoking, alcohol consumption and weight-loss variations across the European countries (Castro et al., 2014). It is important to note however, that a decline in mortality rates does not necessarily demonstrate less diagnoses, or early diagnosis of the cancer and instead may be reflected from the evolution of treatment (chemotherapy, radiotherapy, chemoradiation and surgery), which has clinically evolved over the 31 years.

Other global studies have shown that there has been a significant increase of adenocarcinoma of the oesophagus in men, which seems to reflect the increased uptake of smoking, alcohol intake and obesity (Dong & Thrift, 2017; Sewram, Sitas, O'Connell & Myers, 2016; Xie & Lagergren, 2018). It is therefore suggested that habitual factors such as smoking or weight-related issues such as obesity lead to a carcinogenic effect and abdominal pressure respectively, which may contribute to the development of adenocarcinoma (Devesa et al., 1998; Yuan et al., 2011).

More research is required to shed light on other-cursors of OC, such pre-existing Upper GI conditions like Barrett's oesophagus (Gregson, Bornschein & Fitzgerald, 2016; Solaymani-Dodaran, Logan, West, Card & Coupland, 2004; Umar & Fleischer, 2008). Further to this, Stapley et al. (2013) suggest a number of symptomatic and bio-medical markers that are independently associated with OC: dysphagia, reflux, abdominal pain, epigastric pain, dyspepsia, anaemia, nausea and/or vomiting, chest pain, weight-loss, thrombocytosis, low haemoglobin levels, high blood inflammation, raised hepatic enzymes, raised white blood cells and high cholesterol.

1.6.2 Delays in OC Diagnosis

The majority of the research within the medial field has focused mainly on the delay in patient diagnosis and in turn, the factors that lead up to a late diagnosis of OC (Delaney, 1998; Lewis, Marcu, Whitaker & Maguire, 2018; Macdonald et al., 2006; Macleod, Mitchell, Burgess, Macdonald & Ramirez, 2009). Such studies have identified issues such a lack of patient awareness and patient education about OC symptoms, which are seen to have a direct effect upon the presentation of 'alarm' symptoms to a general practitioner (GP) (Tentzeris, Lake, Cherian, Milligan & Sigurdsson, 2011). One notion for late diagnosis is thought to be potentially associated with the delayed referral of the patient for an endoscopic procedure and specialist gastroenterology care/treatment (Macdonald et al., 2006; Macleod, Mitchell, Burgess, Macdonald & Ramirez, 2009) as well as patient late presentation of symptoms to their GP (Niksic et al., 2016; Smith, Pope & Botha, 2005; Tentzeris et al., 2011; Whitaker, Cromme, Winstanley, Renzi & Wardle, 2016).

Similar to the results found by Mitchell, Pickwell-Smith and Macleod (2015) and Macdonald et al. (2006), the presence of co-morbidities were also associated with an increased delay in the recognition of alarm symptoms as this had possibly masked or deferred the attention of from the main cancer symptoms experienced by a patient. In relation to 'practitioner delay,' Macleold et al. (2009), also highlight the issue of misdiagnosis occurred as a result of treating patients symptomatically as opposed to initiating investigation of underlying pathogenesis through means of referral.

The most common assumption within the literature of help-seeking in relation to cancer is that patients do not consult their GP voluntarily even when experiencing these 'alarm' symptoms. An important study by Mitchell, Rubin, Merriman and Macleod (2015) looked at the issue of diagnosis delay from both patient and doctor perspectives. They looked at the diagnosis of patients via emergency presentation. This qualitative synthesis of patient 'significant events' were grouped to investigate the main factors leading up to diagnosis at the emergency department (ED). Various cancers, including upper gastrointestinal (GI), were included where it was found that the majority of patients had in fact had previous contact with their GP prior to diagnosis, which was within the last three months of being admitted to the ED. Eight patients included within the synthesis had not contacted their GP in the time leading up to emergency presentation, however for the majority of the patients, the main agenda of their GP consultation was to gain advice about their symptoms.

Mitchell et al. (2015) suggest that the primary care input for these patients was extensive however, issues in the recognition of possible cancer symptoms and lack of referral primarily occurred due to patients' co-morbidities and the complex nature of the presentation of these symptoms. A few cases were identified as demonstrating a missed opportunity for earlier referral, e.g. treating a patient with medication leading to the masking of symptoms. Other reasons for poor timely referral was attributed to 'normal' routine biomedical tests that in turn, 'reassured' the GP that a patient's health was fine. It was found that although follow-up appointments had been made by GPs, patients' health conditions acutely deteriorated within this time. As this paper was a synthesis of patient experiences, an in-depth understanding of the nature of the complexities is still undiscovered, along with the patient symptom complexities as perceived by primary health care practitioners who inadvertently delay referral in the first instance.

A previous significant OC study by Rothwell, Feehan, Reid, Walsh & Hennessy (1997), looked at the specific factors affecting the interval between the start of symptom experience until definitive treatment. One barrier noted was that patient treatment was delayed due to the patient's own lack of knowledge of the 'sinister' symptom of dysphagia, even after taking prescribed or self-bought anti-secretory medication that failed to alleviate the 'alarm' symptom. It was found that the majority of patients with dysphagia typically waited three months or more until receiving treatment. The research

suggests that patients are aware of certain alarm symptoms but not necessarily about the importance of these; what they may indicate and if they should immediately present these symptoms to the GP. Another major delay in treatment that the study found was that participants were not referred for specialist investigations upon first presentation of symptoms. Two or more visits or a consultation with another doctor was made before a referral for endoscopy was initiated; something which was also found by Lacey et al. (2016). Although useful, the study encompasses both referral and diagnosis as a whole and fluid process.

Other barriers, such as having a low socio-economic status, have been a recurrent theme in the multiple contexts of health help-seeking behaviour, in relation to identifying and acting on possible cancer symptoms. Macleold et al. (2009) emphasise that there is strong evidence to suggest that there is a significant, positive association between low socio-economic status and the delay in symptom presentation in those with upper GI cancer. A more recent study by McCutchan, Wood, Edwards, Richards and Brain (2015) within the context of socio-economic status and patient outcome showed that both general cancer symptom knowledge and actual presentation time was the poorest and longest in the lower socioeconomic groups. It was found that common alarm symptoms such as lumps and bleeding encouraged timely symptom presentation to the GP, in contrast to non-specific symptoms of a cancer which were not well recognised, therefore suggesting that obvious and physical markers are more helpful in acting as motivation or a cue to seek help from the doctor. Within the context of OC, it could be argued that 'lumps' in the earlier stages of cancer may not be as clearly identifiable as other caused by cancers such as breast cancer. Again, demonstrating the complexity of assessing possible alarm symptoms without visible cues for initiation of referral.

Similarly to McCutchan and colleagues (2015), Niksic et al. (2016) conducted a large-scale national study and found that the awareness of cancer symptoms was significantly lower in minority ethnic groups when compared with the White, British population. The lowest awareness of cancer symptoms was seen among Black Africans and Bangladeshis. This finding was also parallel to the reporting of barriers, with ethnic minorities more likely to report help-seeking barriers. South Asians reported the issue of emotional barriers such as lack of confidence to talk to their doctor. The White British population, however, were more likely to report their worries of wasting the doctor's time. Interestingly, Black Africans had the lowest perceived barriers compared to any of the other ethnicities, for example, no worries relating to wasting GP time for healthcare advice. All of these issues combined helped to highlight the range of personal and cultural factors within the UK, affecting the time in self-referring to the doctor for cancer-related symptoms.

1.7 Research Interest and Background

During my Master's degree in health psychology, I had multiple paid jobs as I knew that practical experience in healthcare and real-world contexts would supplement my studies to help me understand the application of the behavioural theories that I was learning about at the time. Being able to see how theoretical psychology applied in the real world with real patients aided my learning even more and I began to see the links between health and psychology more clearly. I was interested in health and knew that my end goal was to work with people and supporting their health. However, I needed further exposure to healthcare settings to be able identify the type of areas I wanted to focus on within psychology and whether I wanted to provide interventions through professional practice or conduct research. After my jobs in hospital, pharmacy and university, I discovered that my interests lay in research with people. This led me to a PhD degree.

During my undergraduate studies, I became interested in pharmacy and luckily had the opportunity to train as a healthcare advisor and dispenser. After working for a few years in community pharmacy, I then applied for a position in a hospital which opened my eyes to the breadth of pharmacy practice, range of drugs and another dimension of patient interaction that I was not aware of whilst working in high street pharmacy. I was also exposed to another 'type' of patient- that of the 'expert patient'. These were people with cancer or chronic conditions such as autoimmune diseases, who knew everything there was to know about their condition and the medicines that they were taking. This was a blessing in my search for contextual health psychology because I ended up learning from patients who would counsel *me* about their doses as I would hand out their medication and would describe their conditions during conversation as a way to demonstrate their knowledge and progress in their health. At times, they would also share some insight about their experiences with their consultants, which made me relate back to theories of doctor-patient interactions and consultation expectations, medical hierarchy and patient inclusion in their own health. This was one of the first times I started to understand the general cancer journey in hospital.

My job in pharmacy gave me more knowledge about the different 'red' drugs (hospital-only medication) and I learnt about chemotherapy regimen which helped me to understand the medical side of cancer when learning about psycho-oncology in my lectures. I found that I began to build a holistic picture about cancer and healthcare and felt that this knowledge would be helpful to me in future research in cancer coping and care (my areas of interest), as I would then be able to comprehend a participant's narrative about the clinical aspects of cancer care. Although this job allowed me to speak to patients face-to-face, I still felt that I would benefit from hands-on experience with people in a healthcare context and so I gained experience as a healthcare assistant (nursing assistant) in hospital.

I worked as an assistant on inpatient wards (hepatology and oncology) looking after patients with liver issues and palliative care patients. I then worked shifts in the medical outpatients' clinic, with alternating shifts between respiratory, neurology, cardiology and gastroenterology. I became interested in the gastroenterology clinic and found out about OC; something that I did not know much about. I was required to work with special patient lists that consisted of those who were urgently referred to hospital from primary care via the 'two-week wait' (2WW) service. I noticed that gastroenterology clinic had the most 2WW patients every week compared to the other clinics that I worked on and became interested in the different upper gastrointestinal cancers. The more I spoke with the clinical nurse specialists, the more I learnt about the difficulties of detecting OC before hospital referral and tests. This was a type of cancer that drew my attention to research that I would like to conduct, to understand how people interpreted its symptoms.

At the time, I also worked as a research assistant in sickle cell disease care for one of my professors and enjoyed the participant interaction and analysis of the data collected. I therefore decided to pursue a PhD in OC and social science.

I was given the opportunity to by Professor Bowrey to sit in on Upper GI outpatient appointments with patient permission, where I had the chance to understand some of the factors for late OC diagnosis from a patient perspective. I feel that all of my experiences have contributed to my ability to analyse and understand Steve's journey, and create this thesis.

1.8 Overview of Thesis

This thesis is divided into six chapters: Introduction, Literature Review, Methodology, Methods, Findings and Discussion and lastly, the Conclusion chapter. The introductory chapter, as already seen, aimed to provide an overview of the context of the research, background to the selected case and rationale, a brief explanation of my research interests and relevance to the PhD research and a discussion on the current and longstanding issues in OC literature (diagnosis, referral, delays, help-seeking, patient and doctor obstacles). The second chapter covers the relevant literature related to cancer communication, patient behaviour, dying and awareness, and the reporting of cancer stories in the media. A reminder of the rationale which also stems from the literature review is provided. The study design (single CS) is discussed within the methodology chapter along with the chosen epistemological foundations. Chapter three is dedicated to the methods of the study which outlines the data used, analysis of the data and qualitative framework used to do this. This leads on to the findings chapter of the study that is integrated with discussion. This is presented together, in keeping with CS methodology and so that discussion points are situated within the context of Steve's reported journey. The concluding chapter draws all the facets of the thesis together. This includes novel

findings, methodological contributions to knowledge, implications of the research for future journalistic reporting in personal cancer stories and public health awareness.

1.9 Chapter Summary

This chapter described the context of journalism in cancer reporting, complemented by some of the most recent examples of journalists and broadcasters, who have used their own health as a story to deliver health messages and raise awareness about the type of cancer they were diagnosed with. Background to Steve Hewlett's career in journalism was provided so that readers of this thesis are aware of the high calibre of reporting that can be expected from a person with this type of knowledge and experience, which also supports the decision to specifically study Steve's cancer journey as a single CS. This also supports the rationale of the research that the extensive reporting and documenting of his cancer over the span of his diagnosis through to end-of-life, provided a breadth of data to enable a complete and in-depth understanding of the type of skills that journalists use to report on cancer to audiences. A background of OC and the current issues associated with the cancer were highlighted which provide readers with insight into the potential issues that Steve faced during his cancer diagnosis and care. Lastly, I have written about my interest in OC research so that readers can know my background, knowledge and credentials, and how these have guided me to undertake this CS research. The next chapter offers background to relevant areas of cancer care, communication and relevant journalism reporting and techniques used to investigate health stories.

Chapter Two: Literature Review

2.1 Introduction

In this chapter, I focus upon the relevant literature which has guided the development of the research question and provided background to the types of topics expected to arise within a journalist's own extensive reporting of their cancer. The topics discussed within this chapter are the different methods of communication techniques used in cancer and health; barriers faced when seeking help with health in the Western world; psychosocial and theoretical perspectives on interpreting and coping with dying. Lastly, the discussion extends to the methods used by journalists when reporting on health and disease within the media and how stories are composed and presented for effective raising of health awareness.

In order to guide the literature search and inclusion of literature, guidance was taken from Booth, Sutton and Papaioannou (2012) for creating a conceptual map about the general aspects of cancer and prominent medical and social issues or debates contributing to cancer (and OC) reporting in the media. This map also included theories and areas of study about interpreting 'alarm' symptoms, dealing with the effects of cancer, trialling treatment and coping with dying. These topics were included within the map as these mirrored the types of psychosocial aspects that a person would encounter as part of a cancer journey (from diagnosis to treatment). Themes from the map were identified that related to relevant literature and theories linking to cancer experience, coping, care and communication. After identifying relationships between these themes (synergistic and antagonistic) as advised by Booth et al., I found that this helped me to understand the breadth of the literature related to cancer communication, coping and important aspects related to cancer awareness and reporting. Being aware of these themes (cancer communication, metaphor, cancer coping, dying) helped me to engage with existing literature and theories related to the rationale of the research. Overall, the conceptual map acted as a starting point for commencing reading, appraisal and production of the literature review. In addition to this, an iterative process was used when newly-collated data (see chapter 4) was 'accommodated' (Booth et al.) and was seen as relevant to be included. In this way, the literature review was iterative and constantly updated the more I read and the more I analysed and interacted with the data (Lavallée, Robillard & Mirsalari, 2014).

Due to the nature of the case study (being unique, based on an individual person's experiences of living with cancer, through a journalistic perspective), it was evident from the very early stages of the research and initial familiarisation with Steve's interviews, that the CS would be inter-disciplinary. As such, I anticipated that there would be a substantial amount of literature stemming from health, psychosocial, communication and journalism that would need to be drawn upon to lay a good foundation as background and reasoning for the purpose of this study.

Databases searched for relevant studies as per the conceptual map included a range of repositories for both health and psychosocial journal articles and, communication-journalism articles. Therefore, databases searched were scientific and humanities, these also included manual searches of academic websites and referencing software that has the option to search studies. The list of databases used was as follows: PubMed, PscyhINFO, PsychARTICLES, SCOPUS, SAGE Journals Online, JSTOR, Google Scholar, Web of Science, the DMU journal article search, Academia.edu, CINAHL, Mendeley (study search option).

While the detection of these areas was not systematic in themselves (the conceptual map was used to identify relevant themes of relevant themes within the literature), the assessment of studies discussed within this chapter were appraised using the Critical Appraisal Skills Programme (CASP) tool (2019).

The CASP tool (2019) standardised my evaluation of each study and helped me to think about the studies systematically, based upon the extent, or lack of, of journalist issues surrounding the interpretation and communication of cancer studies and public health information covered in reporting. After reading each paper, I was able to make a judgement about the study's importance in being included within the literature review. In order to lay a foundation for journalism in cancer, it was essential that a systematic approach was used so that I could easily trace my steps again if needed when re-evaluating a study but also, for transparency purposes.

2.2 Health Communication and Cancer

Health communication has multiple functions such as; informing, instructing, educating, strengthening doctor-patient communications (Coulter & Ellins, 2007; Diette & Rand, 2007; Houts, Doak, Doak & Loscalzo, 2006; Stalker & Elander, 2015), or persuading people (Hinnant, Len-Ríos & Young, 2013) for different health implications, which can include raising health awareness, signposting for health services or promoting a specific patient or healthcare professional responsibility or behaviour (Green, Gonzaga, Cohen & Spagnoletti, 2014; Rueda et al., 2006). In addition, the medium through which the health-related communication is delivered is an important factor in reaching target audiences who may benefit from the purpose of the communication. In the context of health, digital media (radio, television, social media) has different motives and uses for communication with audiences, which is different to other contexts in communication such as face-to-face healthcare appointments with a doctor or nurse (Fleischer, Berg, Zimmermann, Wüste & Behrens, 2009; Ha & Longnecker, 2010; Salmon & Atkin, 2003). Digital media may be used to deliver public health messages to audiences (see 2.2.2) whereby, communication in healthcare settings is very specific and idiosyncratic to the nature of a disease or target specific population (Janz et al., 2017; Salamonsen, 2013). In the context of

cancer, communication is even more an essential and core aspect of the medical consultation that affects the understanding and direction of a person's health.

Some areas within the literature of communication and cancer discuss the use of metaphor and euphemism to aid conceptualisation about the cancer at different stages of the disease (Semino et al., 2017). Euphemism may also be used to 'soften the blow' for a patient (Brown, Crawford & Ronald, 2006, p.31), giving them time to process the change in their health and health status, from healthy to ill (Radley, 1994). There is however, much debate about the usefulness of this type of communication in cancer, with earlier social writers such as Susan Sontag critiquing its over-use and normalisation of labelling those with cancer as 'sufferers', silenced by war and power metaphors (Clow, 2001). On the other hand, communication and language researchers claim for these to be positively impactful in describing the clinical aspects of a person's disease in more accessible language (Schnitzler et al., 2017). However, more recent research counters this proposition (Hauser & Schwarz, 2019) and the literature is balanced with reasons for anti-metaphor and pro-metaphor use in cancer (Laranjeira, 2013).

2.2.1 Metaphor in Health

Metaphors are commonly used to describe or explain cancer and are used to communicate experiences that are considered abstract, subjective, sensitive or complex (Semino et al., 2017). In doing so, these experiences can be comprehended in simpler or concrete terms (Potts & Semino, 2017). Generally, they are helpful in making sense of difficult and foreign concepts and a reality seen in health is that conceptual unfamiliarity is largely present when patients face and experience a serious disease, and so metaphors can be more helpful to aid understanding (Stein, Pearlman & Tate, 2018; Tate & Pearlman, 2016). Therefore, in the context of cancer, metaphors are commonly used by both patients and healthcare professionals, and in society when referring to the existence or effects of the cancer (Hauser & Schwarz, 2019; Magaña, 2020; Sontag, 1978). Semino, (2008, p.1) states that metaphor consists of talking or thinking about *one thing in terms of another*, which allows better understanding of a topic based on the perceived similarity of the concepts in question, use or speech. To understand how a metaphor is used within health, particularly cancer, it is important to firstly understand the conceptualisations of it and what it can represent (linguistically, socially, psychologically) for the individual making use of this linguistic device.

2.2.1.1 Metaphor Background

Early philosophical thinking about metaphor suggests the importance of meaning-making from one's experience of a situation. While once characterised as merely 'decorations of language' in literature, they have been considered in 20th century philosophy to contribute greatly to our understanding of discourse, from scientific, through to the poetic, or emotional elements of human life and experience

(Ricœur, 2003). Ricœur (1975) argued that both the creative and imaginative ways in which metaphors allow for different and novel ways of 'knowing' demonstrates just how effective they can be to describe the world as it is seen, conceptually. Metaphor is a strong analytical technique that can make discourse *appear to the senses* (Ricœur, 1977, p.38), thus making a perception or experience more understandable or relatable to another. Further to this, Kofman (1993) suggests that reality can never be known as a definitive 'thing', and so it is only through the use of metaphor that we can discuss and express a connection to things, not just a description of things themselves.

Numerous authors refer to metaphors differently. For example, in literary theory, writer Kenneth Burke refers to metaphor as a linguistic (or speech) device with many styles (Chrzanowska-Kluczewska, 2012), while others regard it to be a phenomenon that brings light to other phenomena, through its ability to provoke thought (Semino, 2008; Semino & Culpeper, 2002) thus acting as a cognitive device (Hanne, 2015). Furthermore, Kövecses (2003; 2010) takes the stance that we potentially think about 'something in terms of something else', therefore extending the definition of metaphor to be attributable to enhancing thought, cognition (or understanding) a phenomenon in a relatable way through feelings or existing knowledge and experience, rather than being limited to being a linguistic device.

Early work by Lakoff and Johnson (1980) on Conceptual Metaphor Theory (CMT) proposed a similar notion. CMT, by definition, addresses metaphor as 'experiencing', as opposed to merely thinking about something in terms of something else (Semino, 2008). An example of this is being diagnosed with an 'aggressive cancer'. By using this metaphor, an emotion of fear is likely to be elicited for the individual. Therefore, one aspect of this theory attempts to grasp the abstract or personifying nature of a metaphor in demonstrating non-tangible aspects of human nature (feelings, states of mind). Lakoff and Johnson refer to such types of metaphor as *conceptual metaphor.* In addition, the theory advocates that conceptual *domains* are predicates of metaphor. There are two domains: *source conceptual domain* and *target conceptual domain*. An example of these domains can be seen in the phrase, 'illness as war' which entails 'war' as the source and 'illness' as the target. The source frames the target domain thus providing an overall conceptual metaphor. Different source domains achieve the framing of targets in different ways, such as highlighting some aspects while 'backgrounding' others (Ritchie, 2013). An example of this is the contrasting use of framing, which can be seen in the use of 'battle against cancer' and 'on the cancer journey', which demonstrate different actions or perceptions of the experience with cancer.

Parallels are also drawn between CMT and work by Gentner, Bowdle, Wolff & Boronat (2001, p.226), who suggest that metaphor makes use of concepts but in ways that demonstrate analogy. This means that metaphors can establish links between isolated conceptual 'domains' to create, what is described

as *correspondence.* An illustrative example of this consists of the metaphor, 'the battle against the silent killer' (cancer). The two concepts include the action of 'battle' and the opponent, 'silent killer' which are linked by the conceptual theme of war, ultimately creating 'correspondence' between the two. Therefore, this can help to facilitate a general understanding of the struggle in identifying asymptomatic cancers at early stage disease; as seen in OC or colorectal cancer.

As well as conceptualising what a metaphor is and how it can be studied, authors have attempted to create guidelines on how to formally and objectively identify the presence of metaphors in text or speech. The Metaphor Identification Procedure (MIP) (Pragglejaz Group, 2007), is a formal tool applied to texts to systematically identify whether words are used metaphorically through evaluation of their effects and meaning, and whether words are used within a literal or conceptual context. Such tools help to eliminate researcher bias to produce 'authentic' results (Steen et al., 2010) and can be helpful in identifying metaphors used indirectly to portray meaning (Nokele, 2014). In addition to identification, some tools such as the Metaphor Procedure Vrijie Universiteit (MIPVU) (Steen et al., 2010) can contribute to the translation of a metaphor in question, in addition to meaning (Urbonaitė, 2015).

Critiques offered about these tools are that they do not provide guidance on how to falsify whether a phrase or word is used at face-value, which could act as a confirmation when evaluating a perceived metaphor. Another issue is that some speech or text that is regarded as having metaphorical meaning, may have literal meaning or be representative of instances of polysemy (many possible meanings) (McGlone, 2007; Pinker, 2007). Therefore, a tool or theory such as CMT may through bias, pick a metaphorical indication of the word(s) even though it may have been used in a literal manner. As a result, there are no concrete confirmations of the originally-intended use of metaphor with the use of tools or theory. This is simply the case because evaluation of a potential metaphor is dependent upon the researcher's interpretation.

2.2.1.2 Metaphor Use in Healthcare and Cancer

Within the printed media such as newspapers, 'struggle' language such as 'battling' or 'surviving', is commonly used, which typically co-exists with what is referred to as 'sporting' language such as 'beat', 'won' or 'lost' (the battle against cancer) (Seale, 2001). Seale also identifies two other themes in metaphor that are widely used in the media and by people in health generally: `religious' language ('miracle', 'blessed', 'second-chance') and military metaphor. Seale points out that military metaphor is used mostly in the media but not among lay people and argues that prominent writer, Susan Sontag (1978) had shared views on military euphemism that were based on limited knowing of how ordinary people think about and address cancer.

An early article by Lupton (1994) highlighted that metaphor and discourse go hand-in-hand as shown in newspapers and magazines. It was found that women with breast cancer were shown to be disempowered through the use of military-style metaphor overlaid by patriarchy discourse. Lupton found that the media contained baseless insinuations such that women who have a 'fighting attitude' are more likely to survive than women who do not. In addition, aggressive warfare and struggle metaphorical language used in headlines were proposed to cause anxiety, with the use of such language proposing women as being passive in 'macho' and 'medicalised' rhetoric. Ultimately, again leading to portrayed disempowerment of females with cancer. This article therefore aimed to highlight the social damage that metaphor and discourse can create, for people newly-diagnosed with breast cancer when reading about the disease in the media.

The claim that media and society use of battle and struggle language has harmful effects upon lay people is unsupported by social science (Seale, 2001). In addition, Sontag (1978) and Lupton (1994), although write about the limiting and confusing impact of warfare and struggle language, do not provide reference to studies that have investigated people's perspectives upon the claimed effects of such language use. Once again, demonstrating the necessity of qualitative social science research to understand the true impact, views and feelings about these kinds of metaphor in cancer, healthcare and the media (Seale, 2001, 2002). Evidence from media research suggested that journalists and writers need to be more aware of the impact of the metaphors that they use (Hanne & Hawken, 2007). Therefore, Hanne and Hawken recommend that metaphors should only be used if 'factually informative' and can enhance communication about cancer and clinical concepts surrounding it. This is a valid point but can be equally debated due to the subjective nature of interpreting a metaphor as being something that depends on one's own unique meaning-making (Fuks, Kreiswirth, Boudreau & Sparks, 2011; McNicol, 2014), understanding and level of health literacy especially in cases where cancer treatment or testing can be complex to explain and comprehend (Pinheiro et al., 2017).

There is a great amount of the literature surrounding the usefulness of metaphors in illness and cancer. It has been argued that metaphors can help to create joint patient-doctor decision-making and autonomous patient decision-making (O'Neill et al., 2018; Scherer, Scherer & Fagerlin, 2015; Yennurajalingam et al., 2018). Furthermore, warfare metaphors which propose an existence of an 'enemy' (Sontag, 1978), have the potential to motivate and facilitate health protective and health beneficial behaviours such as medication adherence and help-seeking (Kato, Cole, Bradlyn & Pollock, 2008; Khalil, 2012). This contrasts with other studies that state using bellicose enemy metaphors to frame or describe cancer, have negative effects upon *prevention* behaviour that reduce the risk of developing cancer (Hauser & Schwarz, 2015). This includes, sunbathing, smoking and excessive alcohol drinking.

In the context of using metaphors during cancer care and consultations, Casarett et al. (2010) found that when physicians used metaphors, better ratings of communication were reported by patients. Metaphor examples included, 'Your bone marrow is an elephant. It has a long memory. It remembers everything it has ever seen before' and 'the rash will look just like a sunburn'. The effects seen from using these types of metaphor led Casarett and colleagues to conclude that patients had less trouble in understanding medical information and physicians made greater effort to ensure patients understood their health and treatment when asked to use metaphors. Overall, this implies that communication is enhanced between the patient and practitioner through using mutually-understood language. The technique of using metaphors helps to avoid jargon (Thomas, Hariharan, Rana, Swain & Andrew, 2014) and allows the patient to begin to understand the effects of a treatment (what to look out for in their health) and the workings of cancer treatment.

Laranjeira et al. (2013) support this notion of the positive effects of metaphor such that the patient-practitioner relationship and patient trust can be strengthened and maintained through easily-interpreted communication. According to Laranjeira and colleagues, the biomedical paradigm restricts doctor-patient communication, therefore metaphorical dialogue helps to facilitate trust of doctors in the information shared. As metaphors are better understood than clinical descriptions of cancer and treatment, patients feel more confident about asking for further clarification and questions on other aspects of their disease. Overall, metaphors can empower patients with knowledge and confidence which can prompt patient-led discussions with their doctors. Metaphors can also prompt further conversations of health concerns with physicians, without hesitation or experiencing off-putting clinical or technical and medical explanations (Schnitzler et al., 2017). In addition, they are regarded as beneficial, not only during the pre-diagnosis or investigative stages of the cancer, but also the treatment phases (O'Neill et al., 2018); particularly as patients can find it difficult to effectively communicate in decision-making or contributing their thoughts and concerns during the treatment process (Yennurajalingam et al., 2018).

Patients themselves often use metaphors to convey their health or disease experience in general and cancer (Demmen et al., 2015; Gameiro, de Guevara, El Refaie & Payson, 2018; Harrington, 2012), and feelings related to their illness experience and coping (Charteris-Black, 2012; Fullagar & O'Brien, 2012), which can be difficult to express during challenging health situations (Beck, 2017; Gameiro et al., 2018). Although some authors (Casarett et al., 2010; Hanne & Hawken, 2007; Laranjeira, 2013; Pinheiro et al., 2017) advocate the use of metaphor in health by doctors and patients, it is important to note that the use of specific metaphors are shaped by their cultural backgrounds, current social context, in addition to their own values and perception about their health experience (Houts et al.,

2006). Therefore, it can be challenging to identify what would be an appropriate use of metaphor for a range of patients.

To address the issue of finding as close to universal metaphors that can be used to explain cancer and testing, Pinheiro and colleagues (2017) utilised and tested 17 different metaphors in conversation with patients, where it was found that they demonstrated understanding of the metaphor and therefore, the molecular testing procedure. This also led to patients rating the metaphors as useful in their treatment journey. As a result, metaphors are regarded to be instrumental tools in educating patients about difficult clinical concepts that are required to be understood by the patient, even on a basic level so that clinicians can acquire informed consent for important procedures. As such, the use of metaphor benefits patients by increasing their awareness through accessible imagery and language (Coulehan, 2003; Gameiro et al., 2018) and can potentially contribute to vital decision-making in one's recovery for health (Laranjeira, 2013).

Although metaphors are considered to be useful, concerns have been raised regarding the implications of using certain types. Some metaphors used by patients to talk about their cancer have also been seen to be contradictory to their real experiences (Gibbs & Franks, 2002). Common metaphors used in cancer such as 'fighting a war' are considered to have become conventionalised over time such that they are unavoidable in conversation, even if they may not adequately, or in any way reflect the true perception of their illness or cancer in general (Fuks, 2010). Other authors (Demmen et al., 2015; Semino, 2014; Teucher, 2003), similar to Sontag (1978), discuss the conventionalised use of referring to cancer as a battle and an intruder in the body. The military and warfare metaphors are criticised as they enforce and maintain a dysfunctional relationship between medicine and the effort against curing cancer or delaying an early death (Annas, 1995; Granger, 2014; Miller, 2010). This notion leads back to Sontag's (1978) writings of the construction and imagery of cancer, that is regarded as disempowering those with cancer through the simple use of potentially damaging language.

Further to this, Nie et al. (2016) propose that military, or warfare metaphor is problematic due to its ability to stigamtise patients as victims; legitimise a war and, potentially defeat and inflict additional suffering upon those with cancer. In agreement with Fuks (2010), Nie and colleagues also state that using such metaphors removes the human element of illness experience and replaces this with technical and stressful processes of war. This is also heavily supported by Hauser and Schwarz (2015, 2019), who highlight the ineffective use of war metaphor in cancer and in general health as these can de-motivate people from carrying out healthy and health-protective behaviours due to needing to 'surrender' to the cancer and treatment effects and inevitably, losing 'control'. Hauser and Schwarz

(2019) found that war metaphor only encourages fatalistic beliefs, such that nothing can be done if one is diagnosed with a cancer, due to it being a 'battle' or 'enemy' that is difficult to defeat.

Although the content of the metaphor may be inherently negative, a key question is whether these are consequentially negative in meaning, to promote coping, resilience or, create bias or predispose an individual to a certain psychological mindset towards cancer. For example, going to war or being at war tends to imply an act of bravery (Semino, Demjén & Demmen, 2016). In the situation of a person with cancer, they tend to be automatically given the label of 'brave' or 'fighter', also referred to as an identity change, irrespective of their actions in reality or outlook, or coping (positive or maladaptive) towards their cancer (Laranjeira et al., 2013). However, looking at the literature, it is evident that metaphors have many implications for patients and require consideration before being used to communicate with a person with cancer.

2.2.2 Illness Narratives in Cancer

Whilst metaphor is used to creatively provide access to meaning of concepts and practically to simplify difficult to understand medical issues (particularly in cancer as discussed earlier), the context in which a disease is communicated is also an important area in health accounts of experience sharing. Illness narratives contextualise stories and a body of work in the literature of has sought to explain the types of stories that can be told from the individual's perspective.

Illness narratives are dynamic personal accounts of an individual's experience with coping, living or even dying with a serious or life-changing disease (Frank 1991, 1995). With the development and wider access to technology, narratives are available to read or listen to through various mediums such as radio, television, social media websites ('posts', vlogs and pictures) and written autobiographies. According to Ziebland (2004) illness narratives particularly accessed via the multiple platforms on the internet (news or journalism websites and social media) are done so by audiences to make sense of the illness experience rather than to solely find factual or clinical information. Therefore, narratives can be a helpful source of information in understanding life changing experiences post-diagnosis.

2.2.2.1 Narrative Typologies

Conway (2007) explains that there are various forms of illness narratives depending on context, disease and severity of the impact of the illness. A distinguishing element of a narrative is its ending, as this usually provides the 'take home' message for audiences. Conway also states that illness narratives can be complex, non-linear or chronological, yet the expectation can be to have a 'happy ending' which, in cancer experience is not always the case. Understanding the different endings is helpful in identifying the nature of a story and its ending, thus the potential impact or benefit to audiences.

Frank (1995) previously developed existing narrative typologies by discussing three types of narrative in illness: restitution, chaos and quest. Restitution can be considered a ‘success story,’ referring to the return to normal life and adapting back to society after experiencing challenges and changes with an illness. The chaos narrative is different in that it is a non-linear, non-typical story without a clear beginning, middle and end due to multiple health, social and treatment interruptions that an individual has to face. It can be classed an anti-narrative.

On the other hand, the quest narrative as described by (Frank, 1995, 1998) is a historically well-known type of storytelling that can be a heroic tale or a story of struggle and obstacles, helping to illustrate the difficulty that comes with living with an illness. The quest storytelling method describes the actions, obstacles and resolutions in illness experience, where possible and the meaning of this type of narrative is to demonstrate appreciation for what one's disease has ‘brought’ to their life. Thus, Frank states that an explanation of the 'quest’ in hand becomes a source of insight to help facilitate understanding of the unique experiences and difficulties that arise when living with a life-changing illness.

Although Frank (1995) proposes three typologies of illness narrative, he also acknowledges that each narrative can draw upon storytelling elements from one another, which reflects the complexities and vast experiences that can occur in serious illnesses. For example, a restitution narrative about a person’s cancer in remission may encompass parts of a chaos narrative if the cancer were to reappear, drawing on the unpredictability and interruption that the cancer can cause in the individual’s life. Therefore, serious illnesses are more likely to interweave different narratives due to the nature of the disease and the complexities that can arise as a result. In the context of narrating one’s story, Frank compares a storyteller to an eyewitness to their illness and the narrative as testimony to the interviews.

By relating the three typologies to journalist cancer stories in the media, it is worth asking what the purpose of each type of narrative is. Frank (1991, 1995, 1998) outlines the outcomes of each type of narrative which also helps to demonstrate the potential function of using the specific typology. When applied to the example of cancer, restitution is valuable in showing how an individual with their cancer in remission may reintegrate themselves into society, or even back to their original way of living everyday life before the illness diagnosis. The chaos narrative although mainly illustrates the negative aspects of dealing with illness, can helpfully highlight the different types obstacles that one may encounter in the described illness. This adds to a purpose of the chaos narrative which is to help enhance family and friends’ understanding of an illness through depicting the interruptions, difficulties and fragmented experiences that a patient can endure (Thomas-MacLean, 2004).

The quest narrative is the most chronological and traditional journey of illness out of all the narrative typologies. The purpose it can serve is to provide a dynamic account of how an individual's experiences of dealing with the illness and beginning a 'quest' to help one's self to maintain health or increase one's chances of survival (symptom management or treatment), can demonstrate transformation in an individual (Frank, 2001). These accounts from storytellers about their own cancer is referred to by Couser (1997) as 'important work' as they enhance others' chances of survival by sharing experience and obstacles, and how these can be overcome.

Considering the functions of narratives could be helpful in journalist or celebrity narratives in cancer (Ayers, Althouse, Noar & Cohen, 2014; Evans, Chapple, Salisbury, Corrie & Ziebland, 2014; Walter, 2010; Wood & Bollinger, 2020), to understand how their stories may help audiences. Although Frank's typologies are applicable to various contexts in health and social aspects of illness experience, others have tried to critically assess the role of cancer narrative communication in the prevention and control of the disease (Kreuter et al., 2007). Thus, building upon the proposition by Couser (1997) that narratives have an important role of helping others. As a result of assessing the role of narratives, Kreuter and colleagues outline four distinctive capabilities of this: overcoming resistance, facilitating information processing, providing surrogate social connections and addressing emotional and existential issues.

It is important to question if illness narratives, particularly in cancer must serve a purpose for interested audiences. Catharsis for the storyteller can also be a potential function of narratives as seen in autobiographies where individuals remember and reflect upon past experiences, difficult times, regrets and frustrations in their lives as a result of an illness diagnosis (examples include autobiographies from journalist Ruth Picardie, cricketer Yuvraj Singh and author Rachel Haynes). Although not explicitly referred to as a typology, catharsis may be considered in line with other typologies. Frank (1998) and other authors (Williams, 2011) mention that both storytelling and hearing illness stories have the potential to 'heal' and therapeutically help individuals back on to the path of recovery or facilitate transformation, or even help with adaptation to new life processes following a diagnosis of illness.

2.2.2.2 Intertextuality

When referring to and making sense of illness, patients and healthcare professionals often draw upon conventional and socially-derived concepts that are often conventionally used to speak about the presence of an illness or to generally describe it. These are intertextual references which are often commonly known ideas and conceptualisations about a disease which can be used across generations, cultures and locations. Therefore, within health communication, intertextuality is an area of interest when exploring the type of communication that may take place in the context of cancer.

The narratives of lived cancer experience can differ between lay people, journalists and celebrities. However, the one element that generally provides commonality between different accounts and dialogues is intertextuality (see Kristeva 1966). Intertextuality is a literary concept that is considered to influence the way that a subject is spoken about in that themes or concepts are borrowed and can be often integrated without conscious consideration to used in speech or writing (Orr, 2010). These concepts can form part of everyday dialogue and even influence the way that the subject in question is socially perceived, recognised or addressed. This can be seen within the context of the illness narrative, or storytelling with the use of metaphorical framing. A frequent and well-known example is the use of 'battle' metaphor which is frequently used to illustrate the harmful and negative existence of cancer in the body (2.2.1.2).

Orr (2010) states that to some extent, all concepts are 'borrowed' from previous speech or writing. In effect, intertextuality often provides a level of familiarity to the subject in question for readers and listeners of the narrative as it provides context through existing ideas and ways of perceiving things through socially-accepted or well-known themes. These themes and ideas are often taken for granted and may not be tied to our own autonomous thoughts as prior social dialogue often influence the way that a topic, such as cancer experience, is spoken about. This also includes using specific lexes which are more times than not, attributed to something. The repeated attribution of these lexes is what develops the intertextual themes. An example of this within the cancer narrative is to call a person with cancer a 'fighter' or a 'survivor'. These types of words create an opposing image and position the disease as being the 'enemy'. This is something that Sontag (1979) has extensively debated. Although the relevance of such words in a cancer coping context is debatable, the intertextuality of the themes is not, as even within present day cancer dialogue, cancer is still referenced to the 'enemy' and as a 'battle' both socially and medically (Hauser, Nesse & Schwarz, 2017; Hauser & Schwarz, 2015, 2019).

In the context of media and journalism, intertextuality is visible in the accounts of previous journalists and writers in the media such as Dennis Potter, John Diamond and AA Gill who shared their stories in interviews and written works about their cancer diagnoses and experiences using battle discourse and anthropomorphising their cancer to convey the emotions felt associated with having a life-threatening illness.

2.2.3 Media campaign case study: *Be Clear on Cancer*

As mentioned earlier (2.2), health communication is used to raise health awareness among the public through national campaigns in the media, which has the implication of effectively reaching a large number of audiences across a country through television, radio and paper marketing. Another way to raise public awareness about cancer signs and symptoms is to utilise the media and its different mediums available. An example of raising awareness about OC is the 'Be Clear on Cancer' campaign

that was created to raise awareness about oesophago-gastric cancer. The NHS (supported by Cancer Research, UK) released a cancer-specific awareness campaign in 2015 to inform the public about warning symptoms of the cancer with a main aim to prompt help-seeking behaviours within the general public. In doing so, successful implications of the campaign would mean that members of the general public would seek symptom advice, thus preventing a later diagnosis and decreasing the amount of people diagnosed at the advanced stage of the disease.

The campaign relied upon the delivery of health information through television adverts, radio adverts, press releases, posters and digital advertising within GP surgery waiting rooms: all visual tools that are regarded as being more engaging for the public (Garcia-Retamero & Cokely, 2013). Information was aimed at those aged 50 years old and above as this age group is at more risk of developing the cancer (Cancer Research UK, 2015; NHS, 2015). Public Health England (PHE) estimated that a total of 950 lives could be saved annually as a result of the campaign, as indicated by the pilot phase results (PHE interim evaluation report, 2015). A service audit demonstrated that a consequence of the campaign showed that more patient referrals were made to specialist care and endoscopy for symptom investigation, with referral increases for 63% of males and 44% for females. However, a significant increase in oesophageal (or gastric) cancer diagnosis was not observed and the amount of diagnoses did not increase even though there were increased numbers of urgent (two-week wait) referrals.

When evaluating public health action as a result of the campaign, 82% of the adults interviewed about the campaign agreed that the campaign would prompt them to see their GP. However, only 4% of the people interviewed said that they had made an appointment to see their GP to query their gastro-oesophageal-related symptoms. This small percentage of GP appointments may reflect the fact that the annual OC diagnosis equates to 8,000 people being diagnosed from a population of 66 million people.

The campaign was successful in significantly increasing the number of people diagnosed in the age bracket of 60-69. As a result, the detection rate increased by 40%, from 46% of all patients referred to 86% of patients being diagnosed after referral. This high success rate of diagnosis can be attributed to the simple fact that more patients were referred to endoscopy and this increased the chances of detection rate. However, it would have been useful to demonstrate at what stage of the cancer these patients were diagnosed at after being urgently referred. This additional data would help to highlight whether or not the campaign managed to improve diagnosis times, which is the main issue with OC diagnoses but also is the main objective of all Be Clear on Cancer campaigns for different cancers.

The increases in referral for the older age groups also demonstrated one of two things. Firstly, that not enough GPs may have been referring older patients to specialist care and had only starting

increasing numbers as a result of the campaign. Secondly, not enough older patients were visiting their GP to enquire about their oesophageal, or gastro-related symptoms and more referrals occurred as a result of patients booking GP appointments (and possibly requesting for referrals). Although the campaign had helped to increase the detection rate of OC in the older population, there were no other significant diagnosis rate increases found among other adult age brackets. Therefore, it can be questioned whether the implication of increased referrals is overall, a beneficial outcome of the media campaign. The campaign ought to have steered towards making the issue of late diagnosis explicitly known to the general public. Therefore, emphasising the importance of time associated with the presence of symptoms to be at the forefront of the campaign.

A lot of the campaign material consisted of messages that were imperatives or suggestions, such as 'tell your doctor' or 'heartburn for three weeks or more?' These types of messages promote learning of the cancer and its symptom manifestation. However, a shallow (surface) level of learning is created where simple facts, predominantly without context (such as age, importance of co-morbidities, being overweight or smoking), was repeated. Previous research in the communication of important messages shows that shallow learning from facts and figures does not influence public health-related behaviour such as taking up screening, but instead, messages that aim to provide a deeper level of knowledge (through educating) are more effective in facilitating understanding (Austoker et al., 2009).

The Be Clear on Cancer campaign had used fact-based messages which highlighted the basic behaviours that should be followed once symptoms are experienced by an individual. This demonstrates that although media can be used to promote awareness (Hinnant & Len-Ríos, 2009), awareness may not always create understanding. Therefore, health messages may not be cognitively-processed on a deeper learning level and acted upon effectively by target audiences.

Research advocates that it is essential that any form of awareness building (such as a health campaign) is tailored to the audience's social background and cultural norms for a more relatable and effective reception to health messages (de Wit, Das & Vet, 2008; Esteva et al., 2013; Gatson Grindel, Brown, Caplan & Blumenthal, 2004). As well as this, effective messages are required to be communicated within a negative, positive or balanced frame to elicit public reaction and response (Flora & Maibach, 1990; Fung & Carstensen, 2003; Nabi, 1999; Reeves, Newhagen, Maibach, Basil & Kurz, 1991; Rothman, Bartels, Wlaschin & Salovey, 2006; Williams, Cubiella, Griffin, Walter & Usher-Smith, 2016). Although useful, future health campaigns should carefully consider the type of information that is to be communicated to audiences to achieve better learning and awareness of cancer so that public health goals such as earlier diagnosis can be met. Catering information and communication to specific cultures, and people of different health literacy levels is important in preventing late identification of cancer signs and symptoms, particularly in early silent cancers such as OC.

2.3 Barriers in Help-Seeking

Identifying the different types of barriers to help-seeking is essential in understanding the potential effects upon cancer diagnosis delay. These delays can lead to delayed referrals to hospital and life-saving treatment that could have been more effective during earlier stages of the disease.

2.3.1 Psychological barriers to help-seeking and potential effects upon delays

The majority of psychological research in the context of OC has focused on post-surgery experiences in order gain an understanding of the physical and mental hardships endured after life-saving surgery to improve quality of life (Blazeby, Farndon, Donovan & al., 2000; de Boer et al., 2000; Dempster et al., 2012; Derogar & Lagergren, 2012; Headrick et al., 2002; Hurmuzlu et al., 2011; Seenu, Pal & Chattopadhyay, 2001).

Some studies have aimed to provide an understanding of specific psychological and emotional patient factors affecting early diagnosis that results in delays of the diagnosis process. Smith et al. (2005) conducted a qualitative synthesis of international research derived from the healthcare-seeking literature. The study collated and synthesised help-seeking experiences listed within 32 studies looking at various cancers i.e. breast, prostate, ovary, lung, brain and multiple sites. Key psychological concepts that were identified were *recognition, interpreting symptoms* and *fear of consultation.* Smith and colleagues suggest that 'fear' was manifested as a fear of embarrassment or a fear of possible cancer resulting in pain, emotional suffering or death. As a result, this may de-motivate patients to seek the relevant help needed for prompt diagnosis.

A more recent study identified the influence of fear upon patients with colorectal cancer symptoms. Jensen, Hvidberg, Pedersen, Aro and Vedsted (2016), conducted a questionnaire study using the Danish Revised Illness Perception Questionnaire (IPQ-R) to assess the association between cognitive and emotional symptom representations/perceptions (prior to diagnosis) with the time of the patient delay in seeking help. It was found that patients who had a lack of perceived locus of control in their health and treatment, resulted in high patient interval in seeking help from their GP. It was also found that if patients thought that their symptoms would be hard to treat and the path of treatment would be difficult, this would also significantly delay symptom presentation to the doctor. Other cognitive factors such as the perception of potential treatment as being cyclical was also found to be off-putting to patients resulting in an increased presentation delay. This study usefully demonstrates that patients with questionable symptoms tend to think about their near future health experiences (diagnosis and potential treatment).

Another study by Whitaker, Smith, Winstanley and Wardle (2016) showed that patients tend to have an emotional response to their symptom experience, which can trigger help-seeking behaviour or

adversely, creating psychological barriers in seeking help. Participants shared that if there was awareness of the possibility of cancer by performing a self-assessment of symptoms prior to GP consultation, emotional responses consisted of mild to severe emotions such as worry or increased distress. Certain levels of worry acted as an emotional cue to seek help to rule out possible malignancy of an underlying cause for symptoms. In contrast, when a participant had an emotional reaction of fear, medical contact was completely avoided to prevent an official diagnosis, demonstrating the use of ways to protect one's psychological health (de Nooijer et al., 2001). This study has helped the behavioural health literature to understand the interaction between physical and psychological patient health in the context of help-seeking or lack thereof.

A US study highlighted that one major barrier that prevents Americans from seeking help for cancer is finance (Siminoff, Thomson & Dumenci, 2014). Not only is it seen as an economic barrier for the individual but also acts as a barrier to evaluating symptoms in relation to further steps needed to be taken i.e. attendance of a doctor appointment. This type of barrier can lead to patients ignoring serious symptoms, creating a lack in psychological self-appraisal (Leventhal, Leventhal & Contrada, 1997), which is an essential cognitive process for an individual to then be able seek help and transition through the different health stages (presentation of symptoms to a doctor, referral, diagnosis, treatment, recovery). However as discussed by Leventhal et al., progress in health can only be effectively made when an individual evaluates a health 'trigger' or 'stimulus' (a new or worsening symptom).

Contrastingly, a patient within the UK does not have to face an American-style healthcare system and therefore does not have to experience the direct barrier of finance in the early stages of symptom presentation to a family doctor. However, a recent study by Cromme et al. (2016) demonstrated the influence of finance and GP time as a barrier, where it was found that primary care patients were worried about 'wasting' their GP's time for health advice, to the point where this worry acted as a barrier for individuals to seek help. This worry also stemmed from a feeling of 'wasting tax-payer's money'. Worrying about wasting GP time was accentuated when time constraints were visible within the primary care environment. Many participants felt that if symptoms were not persistent, worsening, or life threatening, they would be 'wasting' GP time. Other external factors influencing perceived GP 'time-wasting' was when the individual was found to have been provided with sufficient attention or advice from a nurse or pharmacist regarding symptoms. Lastly the type of relationship and understanding between the patient and GP was also seen to be a major influencing factor upon the patient's psychological outlook when deciding to attend primary care consultations.

A recent study about OC symptom appraisal by Lewis, Marcu, Whitaker and Maguire (2017) has shown that patients' process of appraising symptoms tends to be inaccurate, particularly as most patients

have limited knowledge of the physical indications of OC. This interview study with diagnosed patients helped to shed light upon the triggers that motivate patients to seek medical attention when they experience oesophageal-related symptoms. Results showed that the changing or unexpected symptoms prompted patients to seek further advice from their GP. Other patient-related factors such as symptoms affecting daily life activities, also caused patient concern which ultimately prompted a visit to the GP. The study also usefully explored patients' subsequent psychological adjustment to receiving the diagnosis which explored experiences of emotional responses and making sense of the cancer itself. A limitation of the research is that patients recruited for participation were one to nine months post-diagnosis, with the majority of participants being male. It is possible that the validity of experiences shared long after diagnosis may be affected by recall bias since patients would either undergo some sort of surgical, radiotherapy, chemotherapy, pain management for treatment. As such, this treatment can physically and mentally affect patients with fatigue, therefore affecting their memory. As a result, reported accounts about symptom appraisal and GP interaction may not be correctly reported and documented, possibly affecting results and future early–diagnosis recommendations for those with the cancer.

2.3.2 Social Barriers to help-seeking

Social barriers to seeking help for health symptoms also play an important role in the time taken to diagnose diseases such as cancer, due to the issue of delayed decision-making and delayed actions of seeking help from a medical professional (Cornally & McCarthy, 2011). There are a range of social barriers that interplay with psychological barriers, such as the embarrassment of seeking advice about intimate symptoms (Consedine, Ladwig, Reddig & Broadbent, 2011; Oberoi, Jiwa, McManus & Hodder, 2015; Smith, Pope & Botha, 2005), gender or ethnic differences in symptom awareness and interpretation (Niksic et al., 2015; Niksic et al., 2016), levels of health literacy (Macleod et al., 2009), which can be influenced by the socioeconomic background of a person (Galdas, Cheater & Marshall, 2005).

Taking part in health screening is an important health protective behaviour that is also faced with social obstacles in addition to health help-seeking. Cultural values, beliefs, tradition and religion have been seen to act as barriers to medical checks such as cervical, prostate, colorectal or breast screening (Abdullahi, Copping, Kessel, Luck & Bonell, 2009; Amarin, Badria & Obeidat, 2008; Bayrami, Taghipour & Ebrahimipour, 2015; Consedine, Reddig, Ladwig & Broadbent, 2011; Ford, Vernon, Havstad, Thomas & Davis, 2006). As a result, research has suggested the need for health education programs to target misconceptions, confusion to increase levels of health literacy and understanding, to improve screening attendance and therefore rates of early diagnosis of cancer (Dhaher, 2019; Ford, Vernon, Havstad, Thomas & Davis, 2006).

It is important to note that although screening is useful in detection of early-stage diseases (Coleman, 2017; Pastorino et al., 2019), detection of changes to longstanding health conditions, such as Barrett's Oesophagus (Reid, 2000; Solyamani 2004), and for targeted means for those genetically pre-disposed to certain cancers (Chau et al., 2019; Mikropoulos et al., 2018), there are debates about the instrumental value of screening in cancer, and whether some diagnoses detected via this route can do more harm than benefits to patients. This being because patients may be exposed to treatments that they otherwise would not have been prescribed had their benign growth (of a long time) not been detected (Vogt, Green, Ekstrøm & Brodersen, 2019). Debates surrounding the usefulness of certain screenings bring to light the medical issue of *overdiagnosis* (Davies, Petitti, Martin, Woo & Lin, 2018), where abnormal or internal changes identified by chance through a screening method are diagnosed (benign at the time of detections), subjecting the patient to potentially unnecessary treatment with a view to prevent existing growths from turning malignant, when there is a chance that the growth may not progress at all (however this cannot be known). Johansson et al. (2021) have found that the harms of screening have been under-reported in reviews considered to be credible such as the Cochrane reviews. In effect, Johansson and colleagues' systematic review indicated that the under-reporting of the harms associated with screening, reflects current issues in screening intervention research such as lack of reporting guidelines, which need addressing.

In addition, other researchers question the value of screening altogether. Gøtzsche and Jørgensen, (2013), in their review of the combined statistical effectiveness of breast cancer screening found that for every 2000 women screened, one death will be avoided, and ten women who would not have been diagnosed if they had not been screened, will be treated unnecessarily (overdiagnosis). Additionally, they found no reduction of advanced cancers, showing that the effect of screening in clinical trials is not an absolute reflection of the effect of screening in real life. Thus, the investment into and promotion of screening have been questioned as more people are becoming aware of symptoms through health promotion and education via the media and seeking help themselves when needed (Gøtzsche and Jørgensen). Therefore, although screening has typically been addressed as a health-protective behaviour and the obstacles to non-attendance have been extensively explored in research, the value of this has been greatly critiqued and it may not necessarily be counted as a barrier to healthcare in itself as it could be, in some respects, more harmful than helpful. Other issues like false positive results can strongly affect future adherence or uptake to screening due to trust in prevention-focused healthcare (Román et al., 2011), potentially creating future barriers to help-seeking.

Other social obstacles are related to gender roles, identity and masculinity (Addis & Mahalik, 2003). Within nuclear families, typically women have been seen to be the initiators of health help-seeking, monitoring health and encouraging husbands, children and boyfriends to make and attend health

appointments (Sabo & Gordon, 1995; Seymour-Smith, Wetherell & Phoenix, 2002; Umberson, 1992). These actions have been seen to be traditionally integral to the role of the woman in a family, usually leading to males, to rely on prompts and encouragement from their female counterparts, as opposed to autonomously gaining health attention (Kiecolt-Glaser & Newton, 2001). This is something that is still seen as a strong facilitator of men's help-seeking which is also seen as a positive source of support (Fish, Prichard, Ettridge, Grunfeld & Wilson, 2015).

Research has acknowledged that men do not seek help for their health as much or as often as women do as this can portray a less masculine identity when coping with and maintaining their health and not feeling to be able to emotionally express effects of certain symptoms (Levant, Wimer, Williams, Smalley & Noronha, 2009; Möller-Leimkühler, 2002; Seidler, Dawes, Rice, Oliffe & Dhillon, 2016). Additionally, finding out about a possible illness and receiving a formal diagnosis can create anxiety or fear (Dillard, Scherer, Ubel, Alexander & Fagerlin, 2017; Oberoi et al., 2015), but can also be a threat to a functioning and healthy body which is what a masculine body image and strong identity is in the first place (Sabo & Gordon, 1995). Therefore, men can feel socially-constrained to seek help as a result (Levant, Wimer, Williams, Smalley & Noronha, 2009).

Another reason for decreased exposure to healthcare and delayed diagnosis of cancers in men (Fish, Pritchard, Ettridge, Grunfield & Wilson, 2015), can be due to their perception of threat to their masculinity and expectation to deal with or overcome health symptoms themselves as societal. This is because traditional images of masculinity portray men who do not require help from others (Edwards, 2006). This view however, is changing with the normalisation and encouragement of screening attendance and increased dialogue about men's health in order to break taboo surrounding expectations of men and masculinity (Cameron & Bernardes, 1998; Doyal, 2001; Gooden & Winefield, 2007; Schofield, Connell, Walker, Wood & Butland, 2000).

Even with the gradual normalisation and encouragement surrounding male help-seeking in health, it is worth acknowledging that other, non-gender specific barriers continue to still play a part in the avoidance and delay of help-seeking as discussed in 2.2.2. This includes the perception of 'wasting' a doctor's time. Llanwarne, Newbould, Burt, Campbell and Roland (2017) found that men also adopt a dichotomised view of legitimate service users and 'timewasters', in effect influencing their own perceptions about which types of health issues would warrant an appointment with a doctor. Thus, showing that balance is required between help-seeking and self-monitoring of symptoms. Another point to question about the dichotomised view of help-seeking shown by Llanwarne and colleagues, is the origins of these types of patient views (male or female), which may reflect the busy nature and portrayal of under-pressure health services as seen in the National Health Service (Lacobucci, 2020; Sizmur & Raleigh, 2018). Likewise, authors such as Jansen (2020) have echoed that some medical

interventions may be perceived as unhelpful and therefore it is a plausible belief to not seek help when little value is seen in visiting a doctor. Therefore patient-practitioner communication is an important element in understanding patient expectations and revising or realigning these if needed to help manage illness and eliminate barriers to feasible treatment (Ogden, 2012).

2.4 Theoretical Perspectives and Models of Dying

Dying can be conceptualised in many contexts. In an illness such as diagnosed cancer, where the patient receives palliative care (when curative treatment has been stopped), dying is defined as the remaining time left between a person's organs shutting down and the complete shut-down of their body and mind i.e., death (Kastenbaum, 2000). The end-of-life period can be sensitive, difficult, confusing, emotional and a journey of finding answers to questions that arise as a result of these very issues that draw upon many aspects of an individual's life history (Buckman, 1993; LeShan, 1989). Some prominent issues where a person feels the need to resolve family disputes or significant relationships (Steinhauser et al., 2000), or completing pending activities ('bucket list'), and fulfilling perceived responsibilities where possible, during a pressurised and limited time period predicted by doctors (Aisporna & Erickson-Hurt, 2019).

Philosophers, researchers, doctors and psychologists have aimed to conceptualise what the steps or stages of dying are and how meaning in one's life, at the end-of-life, is questioned and created. In addition, research in psycho-oncology has looked at how mental health and coping in dying can be improved alongside the physical quality of life (Costanzo, Lutgendorf, Rothrock & Anderson, 2006; Greer, Applebaum, Jacobsen, Temel & Jackson, 2020; Hendriksen et al., 2019). Social medicine and psychology has therefore strived to address the holistic needs to support a dying person to improve comfort, dignity and balance (Baker, 2006; Noble & Jones, 2005; Redelman, 2008; Touhy, Brown & Smith, 2005). Models created around and after the time of the inception of hospice care were done so to make sense of the dying process to achieve a standardised or universal model that can describe what the dying individual would experience at the end-of-life (Buckman, 1993; Kübler-Ross, 1969) or how dying is disclosed or not disclosed to the dying person (Glaser & Strauss, 1965). Other authors focused upon the different contexts and responses to dying and therefore have presented numerous models that can be applied to a patient's situation depending on their perception of their nearing death. In doing so, this provides explanation for the types of obstacles that prevent coping with end-of-life experiences (Kastenbaum, 2000, p.227).

2.4.1 The Five Stage Model of Dying

After interviewing, observing and treating terminally-ill patients, Kübler-Ross (1969) developed the theory of the five stages of grief, also interchangeably known as the five stages of dying which was produced to make sense of the type of experiences that arise during the process of dying (Kübler-Ross

& Kessler, 2005). The five stages were proposed to represent the order of the dying experience which consist of, denial, anger, bargaining, depression and acceptance. Kübler-Ross states that the initial reaction to dying is shock of an incurable illness, which results in the refusal to believe the truth about their health, therefore creating denial of the situation. This is followed by anger, followed by bargaining (with God, a higher being, fate or the universe), followed by realisation of disease progression and that there is no longer potential of a cure to increase life expectancy. Ultimately, this realisation results in no longer denying the diagnosis of an early death, leading to 'acceptance'.

Kübler-Ross (1974) echoed that a patient should not be rushed through each of these stages as the individual must experience and learn from each stage in order to progress effectively onto the next stage. However, there is an implicit indication that the end 'destination' is 'acceptance', along with the suggestion that acceptance is the only stage that can enable an individual to work through their fear and sense of loss (Copp, 1998). This also suggests that coming to terms with death is only possible at the later stages of dying. Furthermore, this model is considered as the psychological response to death, which does not take into account the physical conditions or 'physical reality' of dying, which is a necessary aspect to be included within theories of dying, to demonstrate the 'symbolic construction' of dying that is created through aspects of physical and mental interaction (Copp, 1998; Kastenbaum & Thuell, 1995).

A critique of Kübler-Ross's theory was originally presented by Branson (1975) who indicated that the stages were presented as prescriptive and rigid processes in dying, ignoring the idiographic nature of coping by people when dying. In her follow-up volume to the stages of dying, Kübler-Ross (1974) acknowledged that the stages were only indicatory and not a prescribed order of stages in dying. Buckman (1993) tried to address this major weakness in Kübler-Ross's theory, that people generally respond to dying in the same fashion of the stages proposed. Buckman proposed that when people are confronted with impending death, their reactions tend to be in line with their character and how they tend to react to difficulties in their lives. And so, for Buckman reactions to dying are not reflective of a standard dying 'stage' laid out by a formal dying process, but instead the individual's emotions, insights, perceptions and openness to their limited time left to live is what creates the 'stages' of dying relative to their experiences.

Additionally, the much debated stage of 'acceptance' (Friedman & James, 2008), is not seen to be an essential stage for the dying person at which Buckman (1993) had argued that as long as psychological functioning is not affected, (worsened decision-making or increased distress), reaching a state of acceptance is redundant. If a person is able to cope with the reality of dying, then directing them towards acceptance is not necessary as it may not be useful or beneficial to their coping methods (Copp, 1998). Having an accepting attitude of death can, in some cases, have the effect of depression

and desire for a hastened death (Breitbart et al., 2000). Therefore, focusing on practical and psychological coping in everyday life (task-based coping, Corr, 1992), facilitates active coping, helping individuals to focus their energy upon living day-to-day life as opposed to waiting for death, which is a connotation of 'acceptance'.

2.4.2 Partial Models of Dying (and other concepts in dying)

Kastenbaum (2000) offers 17 different 'partial' models to describe the dying process that can be experienced by an individual. These models encompass various types of thoughts, feelings or experiences that occur as a result of knowing that one is in the stage of dying, and how these may affect the individual psychologically, socially and physically. Table 1 depicts the types of obstacles or thoughts a person can encounter during dying stages.

Table 1: Conceptualisations of Partial Models
(Adapted from Kastenbaum, 2000, p.226-239)

Model	Example of thoughts or expectations
Restricted activity	Less activities can be carried out daily.
Limited energy	Conserving of energy and physical strength.
Illness and distorted body image	Impact of illness upon self and identity.
Contagion	Feeling to be a source of danger to others.
Disempowerment	Lack of influence or power in society.
Attributional incompetency	Perceived inability to do things.
Ineffectuance	Lack of control in one's life.
Stress response	Coping with stress and more problems, as a result.
Time anxiety	Too late now to do other things in life.
Loss and separation	Losing contact or relationships with people.
Disengagement	Withdrawing from interactions and responsibilities.
Journey	Going somewhere, journey after death (known or unknown).
Closing the book	Acknowledging things that are being done for the last time.
Performance	Response to stress and questioning one's own behaviour.
Endangered relationship	Fear of losing significant relationship(s).
Struggling brain	Fluctuations or decrease in mental functioning.
Story	Trying to make sense of illness, present situation and life.

The models are simplistic, and generally self-explanatory. They cover a range of aspects of a person's life during the dying process which helpfully highlights the changes in physical, cognitive, social and psychological domains that are affected by the interruption in normalcy of life and health. Social changes such as identity change and change in health status as shown by partial model, 'illness and distorted body image' draws parallels with Raddley's (1994) description of the change experienced in identity and status when an individual is diagnosed with a chronic illness, such that they commonly perceive a distinction or separation between themselves and 'healthy others'. This means that the individual is segregated by view of their illness, which is either physically seen by others or identified by a given label of the disease or disability. Similarly, Kastenbaum (2000) notes that the individual is recognised by an illness and as dying (by themselves and others), which at most times results to their limited time left to live defined only as dying as opposed to still living.

The model of disempowerment acknowledges the lack of social influence that the individual feels that they have upon matters in their own life and as a functioning and active member in society. The concept of empowerment within health and end-of-life research has mainly focused upon patient involvement within their own decisions about treatment and care (Funnell, 2016), but has also attempted to eliminate or overcome the passive role that patients tend to face in traditional medicine practice (Prigge, Dietz, Homburg, Hoyer & Burton, 2015; Small, Bower, Chew-Graham, Whalley & Protheroe, 2013). In comparison, Kastenbaum's proposal related to experiencing disempowerment, encompasses the lack of influence that one has in all aspects of their life, which stems to participation in wider society as a social individual. Although this too is a useful perspective that Kastenbaum offers as potential scenario that a dying person can experience, a consistent issue found within most of the partial models is that they do not address the positive effects that the realisation of dying can have upon the individual.

The models portray negative thoughts or actions that occur when one is at the dying stage of life, with the exception of models: 'journey', 'closing the book', 'performance' and 'story', as these can be interpreted to have either a positive or negative connotation for an individual, depending upon their perception or satisfaction of life experiences. Research conducted upon mentality, outlook, mindfulness, creating meaning from activities and improved quality of life has demonstrated the positive adjustments that dying people can experience (Cadrin, 2006; Carlson, Speca, Patel & Goodey, 2003; Foley, Baillie, Huxter, Price & Sinclair, 2010; Tacón, 2011; Witek-Janusek et al., 2008). This indicates that 13 of the 17 partial models are not inclusive enough or representative of the vast amount of positive or balanced perspectives that dying people can construct and live with for improved quality of life (Leung et al., 2010).

An example of a useful model that does portray the constructive effects of dealing with dying is post-traumatic growth (PTG) (Tedeschi & Calhoun, 1995). PTG acknowledges the presence of a stressful stimulus (for example, news of imminent death) that leads to trauma (shock or extreme sadness) which, by psychological effort such as mindfulness (Zernicke et al., 2016; Zhang et al., 2016) and stress or anxiety reduction can lead to 'growth'; also known as positive changes to a person's life after a difficult event (Calhoun & Tedeschi, 2014). Growth can also lead the individual to focus upon the time that they have left to live, acting as motivation to do things that they would like, to bring happiness, fulfilment and improved quality of life where possible (LeShan, 1989). PTG provides a comparable example to the partial models of dying. It illustrates the instances of positive experiences and adjustment, post-diagnosis of dying, which is a general concept that is hardly covered in Kastenbaum's proposed models, as these are predominantly directed at describing negative outlooks that a dying person can encounter.

In addition, one theory that effectively supplements the model of 'disempowerment', is patient empowerment (Aujoulat, Marcolongo, Bonadiman & Deccache, 2008). Although it can be regarded as the opposite of disempowerment, Aujoulat and colleagues distinguish two types of actions (or outlooks) that can be conceptualised as empowerment. This includes 'holding on' to self-representations and identity so that an illness does not take-over the person's self-concept or, image or status in society and, 'letting go' which refers to a person understanding that they can no longer control their situation and allows the integration of their self and their illness. Both methods are seen as instrumental to the transformational process in gaining full empowerment when an individual's stability is threatened by their health (Aujoulat, Luminet & Deccache, 2007). Although Kastenbaum provides insight into disempowerment, without counterbalancing this with a model of empowerment, it can be difficult to understand the full concept and breadth of disempowerment without the definition of empowerment itself and what the experiences of this could be, or how this differs from disempowerment. This notion can also be extended to models such as 'ineffectuance' and 'disengagement', which are not countered with 'effectuance' or engagement models.

Although Kastenbaum covers a number of different aspects of dying, there are more areas of a person's life (social, domestic, occupational, culture, religion) and concepts such as psychological outlook, adjustment, coping and experiences that cannot all be categorised under the 17 models (Chochinov, 2009; de Nooijer et al., 2001; Glick, Cook, Moye & Kaiser, 2018; Kellehear, 2017; Meisenhelder, D'Ambra & Jabaley, 2016; Nelson, Rosenfeld, Breitbart & Galietta, 2002; True et al., 2005; Welch, Teno & Mor, 2005). The models are arguably a significant starting point for doctors and therapists to identify what a patient may be experiencing based on their views shared and actions observed. However, with the vast amount of intimate, sensitive and unique experiences during the

dying phase that cannot be simply captured by 17 models, it is worth considering whether a catered approach to holistically understand a dying person's personal interpretation and outlook of their life, is more effective in conceptualising the dying process (Chung & Oh, 2016; Noble & Jones, 2005). In doing so, it is possible to help address obstacles unique to the individual as opposed to attempting to match their experience or perception to a labeled category, as this may not contextually represent the dying person's views or the breadth of their experiences.

One author that aims to address this notion is Corr (1992), who proposed a contemporary approach to acknowledge the breadth of experiences and effects that dying has on quality of life and the ability to live life. After taking influence from Kalish's (1979) work on 'tasks of the dying person', Corr produced guidance on coping with dying by proposing a 'task-based approach' allowing for understanding the person-specific needs of the individual through addressing four main areas of task. These include, i) physical, to satisfy bodily needs and reduce physical distress which are consistent with personal values, ii) psychological, which is to maximise psychological 'security', 'autonomy' and quality of life, iii) social, this is important to sustain and enrich relationships in one's life but to also address the 'social implications' of dying and iv) spiritual, an area proposed to reaffirm sources of 'spiritual energy' and fostering hope (Copp, 1998).

Corr's (1992) model offers an alternative to existing models such as Kastenbaum's partial models or Kuber-Ross' stages of dying theory as instead, it offers a task-based approach, helping the individual to broadly address issues for general areas, without having to follow pre-determined stages or categories of dying experience. Thus, helping the move towards a person-centred approach to meeting dying needs and priorities. It is also helpful as multiple issues can be addressed through one type of task area. In addition, the model creates awareness of four predominant areas of challenge and importance and how to deal with them, ultimately facilitating preparation for death (Kellehear, 1993). Again, this is not something that other authors encompass within their models or theories of dying but parallels with spirituality and reconciliation of relationships can be seen with Kübler-Ross' (1974) and LeShan's (1990) work (*Cancer as a Turning Point*).

2.5 Health in Journalism and The Media

Journalism helps to facilitate public knowledge but has other impactful uses such as media advocacy (Wallack, Dorfman, Jernigan & Themba-Nixon, 1993), which consists of communicating and representing public health matters, to promote certain health goals for a nation or specific group of people (Dorfman & Krasnow, 2014). It is particularly prominent for questioning political situations affecting public health funding and scientific developments, but also speaking about governing policies to trigger social change for the benefit of meeting public health goals (Wallack, 2002; Wallack & Dorfman, 1996). In addition, this type of reporting can act as a media intervention or be the first step

in making organisations or governments accountable for issues in unmet public health needs (Bou-Karroum et al., 2017).

Other researchers pose that the media and journalism have the power to affect decision-making of doctors, policy-makers and health professionals due to the ease of accessible information and up-to-date information, at times supplemented with patient stories and expert opinions or interviews (Dentzer, 2009; Metzl, Caplan & Wahl, 2004). Equally, patients are just as likely to be influenced in their treatment and care plans when informed about the latest medical news. An example of this is documented by Haas, Kaplan, Gerstenberger and Kerlikowske (2004), where a temporary declining use of hormone therapy in post-menopausal women was observed after the publication of the treatment side-effects and possible future illness development.

The common purpose of journalism is to teach and inform people of note-worthy topics and events in the world through effective techniques such as storytelling to make the unknown, known (Thompson, 2019). In health and cancer, journalism is a key method of providing information to audiences about current and important issues, world-wide developments and future prospects of health and medicine (Eggener, 1998; Safari, Baratloo & Yousefifard, 2015; Shuchman, 2002). Therefore, journalists are vital facilitators of knowledge for lay people who rely on the latest research and study results to be interpreted by journalists, for dissemination of this information through the media (Appiah, Gastel, Burdine & Russell, 2015). Although efforts have been made to understand the ways that health journalists report information, there is only a limited body of research about their methods used for interpreting scientific results and conclusions, use or the lack of use of evidence-based reporting and framing of lay people's cancer stories.

In order to understand journalists' own viewpoints about their role, Chew, Mandelbaum-Schmid and Gao (2006) interviewed eight journalists to highlight how they choose to report about cancer and mammograms, and in what ways this is done. The authors found that journalists tended to provide practical advice over scientific conclusions and lacked recommendations to prevent unnecessary panic in women about cancer screening. Chew and colleagues point out that these types of reporting choices can affect the validity and trustworthiness of information presented to lay audiences. It is also important to therefore consider whether the reporting of practical information and advice, over scientific guidance, is likely to affect timely attendance of breast screening and affect earlier detection of the disease in those audience members who decide to follow this journalist-reported information.

2.5.1 Reporting Inaccuracy

It is possible that some journalists choose to report practical information as opposed to scientific knowledge due to the target audience's reading level and ability to understand the science and

research behind medical findings (Friedman, Tanner & Rose, 2014). Instead, audiences are perceived to benefit from knowledge of what actions to take for their health. Chew et al. (2006) question whether some journalists are confident in being able to interpret scientific studies to then be able to bring valid and up-to-date guidance to audiences. Schattner (2017) points out that journalists can 'spin' statistics, which can be irresponsible in bringing the truth or the scope of an issue to audiences. These types of 'spins' to data or reporting findings out of context (something as being carcinogenic) or not providing the full picture of a study (early trial results) can create further challenges in disseminating appropriate information to lay audiences, as well as creating worry that is unwarranted (Chang, 2011; Russell, 1999).

As echoed by Schattner et al. (2017), factually valid and scientifically based information in journalism is necessary and important due to the impact it can create upon audience knowledge and trust of information received. This is particularly the case in some countries where journalism is relied upon in the absence of the internet and social media, for all relevant and up-to-date information of what is happening in the world, and for scientific developments (Appiah, Gastel, Burdine & Russell, 2015). Okorie, Oyesomi and Kayode-Adedeji (2014) advocate that journalists bridge the gap between information and the public through communication on written, audio or visual media platforms. The authors conclude that health journalism is essential in Africa to promote breast cancer awareness among women, where healthcare access and quality of care is progressive (through modern Western medicine). This type of impact journalism, in this case, is addressed as *developmental journalism.*

Although it is necessary to maintain factual reporting in health to enhance knowledge, disease symptom awareness and help prevent illness in audiences (Berry, Wharf-Higgins & Naylor, 2007), some news coverage can evoke fear and increase perceived vulnerability to, or severity of a disease (Chang, 2011). According to the study by Chang, in these instances, such reports may not help with illness prevention or perceived treatment efficacy. In addition, coverage needs to be focused upon improving health knowledge to help prevention or detection of disease. Although these are valid points made by the author, claiming that reports should affect perceived treatment efficacy is a broad and unmeasurable proposition as treatment is not a standardised or universal procedure in cancer as various specialised treatments are prescribed according to the type of disease, patient among other factors such as treatment scope (Alazzam et al., 2016; Bromham, Schmidt-Hansen, Astin, Hasler & Reed, 2017; Ferguson, Wilcken, Vagg, Ghersi & Nowak, 2007; Thamronganantasakul, Supakalin, Kietpeerakool, Pattanittum & Lumbiganon, 2018). As such, improving health knowledge and disease awareness is a more realistic and achievable goal through journalism (Slater, Long, Bettinghaus & Reineke, 2008).

Specialist health and medical reporters have better technical knowledge compared to non-health trained journalists (Leask, Hooker & King, 2010; Veloudaki et al., 2014). After assessing questionnaire responses from 34 journalists, Keshvari, Yamani, Adibi and Shahnazi (2018) found that those who are not specialist-trained in reporting medical or health stories found it difficult to understand health issues and knowledge of medical terms were moderate to low. The authors arguably state that the most valuable and required skill for journalists is to interpret research reports and scientific reports. However, this can only be successfully done if understanding of medical concepts and terminology is good.

Interviews with scientists carried out by Maillé, Saint-Charles and Lucotte (2010) found that journalists were seen to lack accuracy in their health stories released in the media. In comparison, journalists perceived that the problem in the accuracy of information stemmed from the vast amount of evidence released by numerous studies in the scientific field, creating a lag between information reported and up-to-date findings. The lack of time given to journalists to report about new developments to audiences about complex medical advancements or clinical trials, has also been seen to be an obstacle for journalists to be able to provide a critical perspective on ground breaking health news (Larsson, Oxman, Carling & Herrin, 2003). Therefore, issues such as inaccurate reporting can be due to the lack of focus on the multiple aspects in a study and not providing a whole account of the study findings and implications. As a result, some health journalism reports are seen to be inaccurate as opposed to incomplete (Clarke & Van Amerom, 2007; Maillé et al., 2010, Ashoorkhani and Majdzadeh, 2012).

Amend and Secko (2012) also found instances of journalist reporting to be incomplete, sensationalised and failed to engage audiences in meaningful dialogue about the health topic in question. Again, similar to Schattner et al. (2017), the authors enforce that journalism ought to have positive impact upon audiences using factual, up-to-date and complete information using credible and valid sources. However, such critiques can be challenged such that it is not always necessary to report on all aspects of a health news story as this can confuse audiences and steer them away from the main 'take home' message of the report.

Critical questioning of health research and scientific methods, such as participant backgrounds, significance levels, contexts, generalisability of findings to other health situations and influence of confounding or extraneous variables, although important (Appiah et al., 2015), cannot be feasibly covered within reports that aim to disseminate significant 'take home' messages to mass audiences of varying reading levels. To tackle criticism of the quality of content presented to audiences, Nelkin (1995) recommended goal-based reporting backed by science to create impactful and focused health reporting. However it is still not clear as to why inaccuracy of information has not improved and is still

a prominent issue with journalism even after many other study recommendations, and training programs for improving health knowledge and dissemination of this (Appiah et al., 2015; Ashoorkhani & Majdzadeh, 2012; Keshvari et al., 2018; Valentine, 2005).

The in-depth study by Amend and Secko (2012), investigated the lived experiences of science and health journalists through qualitative synthesis of study results to understand how the widespread criticism of the quality of journalist reporting is perceived. The authors echoed that this is a valuable perspective to explore, for scholars who aim to identify issues with health and scientific reporting to meet the challenges the profession. For example, the challenge of engaging audiences with meaningful and helpful health information. A major theme was found to be 'sourcing practices', where journalists retrieve and chose data from sources to form the basis of their news story. Journalists working in the mainstream media work under a strict time pressure and therefore accessing data and findings can be limited if in-depth and wider searches are not conducted or only one source of information is relied upon. This can lead to incomplete or biased stories as the interpretations of findings or alternate explanations for stories are not presented. Therefore, when more time is dedicated to a story, journalists are more likely to contribute more meaningful and complete stories to audiences.

Amend and Secko (2012) also found that sources used by journalists that placed a story or information into context was more likely to be explained with scientific and medical concepts being translated into everyday language for audiences. For journalists to be able to understand the concepts in question themselves meant that they could explain these better and use appropriate examples and draw valid conclusions and advice for audiences. Hence, making scientific news contextual, more accurately reported and information more easily understood. As echoed by Knight (2011), journalists' competence and their effort to understand concepts of findings, as opposed to merely repeating these in reports, is essential in delivering correctly-interpreted information to a lay audience. In addition, the repetition of information, without simplifying it for the benefit of audiences with varying reading or health literacy levels, is not as effective in truly informing and educating people about the latest scientific developments and health advice (Hong, 2013).

2.5.2 Human Interest Framing

Framing of news is an important paradigm to provide context, create public responses from listening to, reading or viewing news (Hallahan, 1999). This is closely linked to news discourse, which is defined as a 'sociocognitive process' involving three aspects: sources, journalists and audiences in the space of a shared culture, societal norms (Pan & Kosicki, 1993). This can also include social priorities, such as cancer prevention or early detection of disease, as mostly seen in western and developed countries (Balata et al., 2019; Durkin, Broun, Spittal & Wakefield, 2019; Ginsburg et al., 2020).

Human interest framing (HIF) is a type of news framing which focuses on the personalisation of a news story through human example by providing anecdotes and real-life experiences or views to uphold the story (Boukes, Boomgaarden, Moorman & de Vreese, 2015; Hong, 2013; Viswanath et al., 2008). Some studies within the journalism literature generally refer to HIF as 'exemplars' or 'personalised stories' (Andersen, Skovsgaard, Albæk & de Vreese, 2017; Brosius & Bathelt, 1994; Greene, Campo, & Banerjee, 2010; Hinnant et al., 2013). Although a widely-used technique in journalism, some public health officials have urged not to use framing for health that focuses upon individuals but rather to promote broader societal framing within news coverage (Holton, Lee & Coleman, 2014). It is important to note that not all exemplars used within the media and reporting are framed around human experience or stories but are used frequently to exemplify and contextualise a current issue (Bigsby, Bigman & Martinez-Gonzalez, 2019).

A study by Hong (2013) on HIF in news reporting suggests that audiences are more likely to be interested in stories that use this method of reporting as providing an individual's example are easier to understand by lay people, triggering more social impact of a story in comparison to purely scientific-reported information. The participants of the study were given a news story about technological advances in medicine using HIF where it was seen that the perceived social impact of the medical advances influenced favourable opinions of the medical story. Although HIF can be instrumental in influencing audience perception and understanding of a news story (Aalberg & Beyer, 2015; Hong, 2015), it causes audiences to morally evaluate a story based on the individual's perspective, as opposed to acquiring a true or objective understanding of a topic and its wider implications for health (Hong, 2013). Therefore, focusing upon a micro picture of experience as opposed to the bigger picture of science and medicine is counter to one of the goals of journalism, which is to teach and educate audiences of facts (Mindich, 2000).

As HIF can facilitate learning in audiences through using relatable people and their stories, it is still helpful to use the technique, however journalists should be responsible in their reporting to provide objective information and advice embedded within or in addition to HIF (Holton, Lee & Coleman, 2014). A similar notion is put forward by Boukes, Boomgaarden, Moorman and de Vreese (2015) such that although HIF is an influential strategy, it is not enough on its own to provide a complete and accurate representation of issues without having scientific facts or evidence reported alongside it. The authors discussed that the use of HIF examples to demonstrate political decisions, policy and social reform influenced audience perception, such that audiences attributed the conveyed issue as purely being governmental responsibility, relinquishing any other type of responsibility such as public or corporate responsibility. Therefore, exemplifying the consequences or effects of political

developments through HIF, had the power to affect audience's personal attitudes about the responsibility for a social, health or economic issue, due to the wider context left undiscussed.

Hinnant et al. (2013) provide criticisms for the use of exemplars (or HIF) for the reason that its use by journalists have raised ethical concerns, such as deliberately shaping a person's cancer story to 'fit' the current news climate or stereotype to gain more readership. It was found that the journalists tended to deligitimise an individual's real demographics or character, or social traits to make them seem middle-class, with a 'good' image so that readers would be more likely to engage with the story and take it more seriously. These instances of reporting, which were self-reported by journalist participants, is pseudo-journalism where HIF was used incorrectly. This is something that is cause for concern in reporting in addition to the misinterpretation of science (Maillé et al., 2010), when bringing stories to audiences due to the shaping and changing a person's health story. This can lead to the misrepresentation of the truth and raising awareness based on unreal life events.

Hinnant and colleagues (2013) also echo that exemplars produce emotional 'investment' by drawing the reader's interest to a personalised and sensitive story, as opposed to factual and useful information that can lead to the education of identifying potential illness symptoms, important treatment developments and general health awareness. Kreuter et al. (2007) have argued that although useful in providing humanised stories to audiences, some narratives from lay people can lead to inaccurate information about cancer, treatment, diagnosis and survival. This is demonstrated by the fact that lay stories are subjective, based upon personal and unique experience and perception. In turn, affecting the credibility of an intended health message. Although Kreuter et al. support the usefulness of exemplars, these are suggested to be used appropriately for meaningful and purposeful reasons. They are seen to facilitate awareness in people with lower levels of health literacy through relatable stories, helping overcome the lack of interest in reading or listening to health or science news containing jargon which may not be easily understood by lay audiences.

In reviewing medical and health reporting guidelines, Vercellesi et al. (2010) found that anecdotes or anecdotal stories should be avoided. Similar to Kreuter et al. (2007), the authors provide advice for the use of HIF such that if used, these should be upheld by scientific facts and evidence to ensure true representation of the health phenomenon and therefore, provide factual and trustworthy reports even in the context of a personalised story. This is one way to prevent misleading health awareness. Vercellesi et al. also distinguish that there is a great difference in public health value and journalistic value in the use of HIF and exemplar stories, which is that journalistic value through sensationalised (Amend & Secko, 2012; Grabe, Zhou & Barnett, 2001) and uniquely reported cases, lack in raising disease awareness or fact-checking in health.

In addition, journalism that relies on exemplars in the form of lay narratives, or a sensitive and humanised approach (Hinnant et al., 2013), inherently draws upon (lay) audience's emotions to guide their interpretation an article or report based solely on the personalised and sensationalised story. Therefore, the influence of a sensationalised HIF story (without or with limited facts), can outweigh the importance of science, side-tracking noteworthy, accurate, beneficial, and potentially life-saving information for audiences to know and remember for future health disease (Boyce, 2006; Schwitzer, 2008).

Although exemplars in health and in cancer in particular, can lead to the questioning of validity and credibility of the health information (or experience) shared, it still can provide a vivid description of cancer stories more than general health and factual information (Brosius & Bathelt, 1994), more so than simple facts and figures (Schattner, 2017). When used correctly, exemplars used in the media can also create vivid recall of information (Andsager & Powers, 1999), generate thoughts, reactions, personal reflections and create dialogue or 'health talk' among the public due to the interesting and humanised nature of the story supplemented with hard facts.

As voiced by Hinnant and colleagues (2013), irrespective of the credibility or validity of information reported through HIF or exemplars, these play a significant and essential role in gaining audience attention, maintaining their interest and potentially influencing their perception of the extensiveness of a health issue and attention to a health awareness message. The main issue as shown within the body of health journalism and its reporting techniques is that using lay cancer stories raises questions about the lack of scientific facts and the correct interpretation of these within a personalised context for audiences.

2.6 Rationale as per Literature Review

The use of lay examples in cancer reporting poses quite a few challenges as discussed. Therefore by this logic, cancer stories voluntarily presented by journalists about their own diagnosis and treatment experience is more likely to provide quality and impactful journalism to audiences, with clear goals for public health as the story is personal and meaningful to the journalist themself (as seen by the examples given in 1.2.1). In addition, the need to sensationalise a story or mould it to fit reader interest is something that personalised reporting by journalists can tackle and still deliver originality in stories that newspapers and news channels highly value to set themselves apart from the news outlets (Knight, 2011). As HIF in cancer reporting is regarded as a highly successful way in engaging audiences with a story, it is worth-while investigating a strong example for how it has been used by a journalist to deliver their own cancer story in the media. Steve Hewlett was an experienced, skillful and commended journalist who had a keen eye for facts (see for 1.3.1 for career history and endorsements), which is why Steve's reporting of his cancer was chosen to be studied in depth.

Furthermore, exploration in to how he communicated as well as the content is just as important. This included exploration into how the personal human experiences and feelings related to cancer can be journalistically intertwined with the facts and practicality surrounding diagnosis, treatment, and obstacles in living and preventing early death.

2.7 Chapter Summary

The literature review within this chapter has aimed to provide background to different areas within cancer care, and communication and journalistic influence on the delivery of health-related facts and public health awareness messages. Cognitive linguistics, such as metaphor, commonly used to describe and explain cancer, are strong methods of communication, as are public health messages campaigned to raise awareness, prompt timely detection and prevent early death from the disease. The literature reveals methods used by journalists to investigate and create cancer stories, nonetheless there is limited research upon how a journalist uses legitimate and professional techniques to share unique health journeys with audiences. This notion led to the rationale of the research.

Although this chapter covers a range of different topics that are not distinctly related to each other, they reflect the breadth of areas that impact an individual's perception, knowledge and experience of cancer; something that was also reflected within Steve Hewlett's extensive reporting of cancer, which included the pre-diagnosis stages up until the stage of preparation for death (as discussed in chapter 5). The next chapter focuses on the philosophical underpinnings of the research, with in-depth discussion on the nature of a qualitative CS and technicalities related to the methodology.

Chapter Three: Methodology

3.1 Introduction

The purpose of this study was to inductively explore Steve Hewlett's journey with OC and to understand the psychosocial, medical and journalistic approaches he used in the media to raise awareness of the cancer and educate and inform the public about such experiences. In this chapter, the theoretical and methodological considerations of a case study (CS) and, the philosophies adopted which were used to underpin the analysis are discussed.

The chapter is separated into discussion about the foundations of the CS methodology, including background, strengths and limitations. Important CS procedures such as defining case boundaries, performing triangulation and outlining research propositions (Yin, 2013) are explained and how these were implemented for the purposes of this study. Ontology and epistemology are discussed in terms of their theoretical and practical uses for analysing Steve's experiences of cancer in a healthcare setting, the impact of the disease on him and how he used his journalistic skills to raise awareness of being diagnosed and coping with OC. Further debate on the aims and use of the epistemology of interpretivism (hermeneutics) is provided with an aim to highlight its usability and appropriateness in the deconstruction of the various segments of the cancer journey (diagnosis, hospital referral, treatment, clinical trials, palliative care).

The need to personally and professionally reflect, as a researcher, on the inherent subjectivity of the chosen epistemology is also regarded as an important aspect of qualitative research. This was particularly important within this study as the data analysed was collated from a pool of existing media (radio and television) interviews, which had not been influenced by a proposed research question or goal. The reliability of such data, uninfluenced by a research agenda, is addressed (with further discussion of this in chapter 4). However, the number of obstacles faced when analysing seemingly incomplete descriptions of experiences is also acknowledged through the practice of reflexivity.

3.2 Case Study Methodology

CS methodology was the chosen methodology for this research as this approach allows for an in-depth exploration of a research topic, whether that be a person/people, events in time or social structures (Thomas, 2015). Within social research, the aim of case studies consists of discovering, identifying, describing and analysing the occurring concepts within a social situation (Yin, 2009). It is a research design that is helpful in understanding a contemporary phenomenon within its real-world context (Yin & Davis, 2007). The most prominent feature of CS methodology is that a phenomenon is comprehensively researched, through the use of multiple sources and validation techniques such as

triangulation (McGloin, 2008). With the use of these extended techniques, a case report is created in a holistic and in-depth manner (Bassey, 1999).

3.2.1 Background and Use

The known history of CS dates back to the 1300s in the areas of anthropology and social sciences where it was used to understand different cultures, societies and practices through overt and covert observations and carrying out in-depth ethnographic-like studies (Merraim, 2009). A well-known historical example is the use of CS by Charles Darwin in the 1800s when documenting his own observations and collecting evidence for research about human and animal emotions (Kohn, 1985).

During the 1940s and 1950s however, there was a positivist focus within the social sciences, in particular within psychology; with focus upon testing and understanding decision-making and behaviour. There was a drive to use quantitative methods to investigate links in an effort to provide solid and replicable evidence that could either confirm research hypotheses (Harrison, Birks, Franklin & Mills, 2017; Merraim, 2009), or 'falsify' them (Popper, 1963).

In the past, psychologists and psychoanalysts frequently studied their participants ('subjects') and patients in-depth to gain an extensive understanding of introspection and experiences to develop new theory about human behaviour and personality (Eysenck, 1981; Freud, see Roazen, 1995). Although observations and notes provided unique insights, results were questioned due to the lack of transferability of idiographic case characteristics and these types of studies were often methodologically criticised for the lack of ability to generalise findings, which de-valued CS as a research design, due to this perceived restricted validity (Harrison et al., 2017; R. Johansson, 2003). This became more of an issue with the use of qualitative data in research (Harrison et al., 2017).

There have been unique and controversial case studies in the past during the early and late 20th century. One example includes the 'Little Albert' case study by Watson and Raynor (1920) (see Harris, 1979), where the concept of conditioning was tested through the deliberate attempt to create fear in an 11-month-old baby through association of certain stimuli. Another unethical case study was conducted by Money and Russo (1979) (see Beh & Diamond, 2005) on the life of David Reimer who was given female hormones to reassign his biological sex although he had been born a male. Reimer's behaviour and changes in personality were extensively documented during his life. These disturbing studies used a positivist stance to gain what is known as, 'solid' data (Harrison et al., 2017) and used the both used the same principles in the research design: the CS, which allowed for in-depth, comprehensive and longitudinal study into a participant's or patient's life. Although definitions of CS may have changed throughout the years (Harrison et al., 2017), the general principle of gathering an in-depth and comprehensive amount of information has not changed.

As pointed out by Yin (2013), early studies and text books that discuss CS, limited the possibilities and implications of CS as a research method and failed to elaborate upon the multiple techniques that can be incorporated to illustrate a phenomenon from different perspectives, sources and interpretations to build an informative view of something occurring in the social science domain. This demonstrates the issue of the lack of guidance and standardisation that was developed for CS in the past. In relation to researcher guidance, there is debate as to whether CS is a methodology, method or both (Harrison et al., 2017). However, its evolution of being a pragmatic and flexible approach, with focus upon application can create confusion between CS being a research methodology and research method (Mills, 2014).

The literature surrounding CS methodology is also confusing for a researcher to navigate through due to the lack of standardised use of terminology and definitions given to terms. Creswell (2014) uses the phrase 'case study design', which implies a research methodology. Others simply refer to the term 'case study' without much reference to how it is conceptualised: as a method or methodology (Flyvbjerg, 2011; Raggin & Becker, 1992; Stake, 1995; Yin, 2013). As echoed by Harrison and colleagues (2017), such a mix of terminology in the literature and research guidance can create differences in the understanding of the methodology. This may then create differences in the practice and application of CS methodology research. As a result, a critical question that arises is whether we can be sure that what is being addressed as a CS in a piece of research, is in fact a reliable and general standardised design.

There have been definitional misunderstandings of the CS method and a lack of awareness of the extensiveness of the methodology as a main study design (Yin, 2013). Yin states that previously within social sciences, it was often seen to be a preliminary and exploratory stage of another type of research method or experimental design, as opposed to a complete research method in itself. As a result, past researchers did not fully consider CS research to be a formal and explicit research methodology. With better understanding and effective use of CS for social research impact, this view has now changed (Flyvbjerg, 2006, 2011).

To help address this mis-match of definitions and use of terms, Mills (2014) distinguishes methods as procedures and techniques that are used in the study and methodology as the 'lens' that the researcher looks through in order to make decisions about the type of study to be carried out, the scope of the study (using a bounded system or case boundaries) to materialise a strong design for in-depth inquiry of the research topic. Although useful, separating and designing the two types of CS does not address a one true conceptualisation of CS: whether it is indeed as methodology, method or both. Therefore, this longstanding debate continues to be a vital question for researchers when

considering how CS is to be used and motives for doings so. In the current CS, my position is that CS is a methodology and I have utilised it to create and implement the design of the study.

More recently, within social sciences, CS research has become a methodology in its own right, and there has been an ongoing shift away from the use of words such as 'influence, 'cause' or 'dependence' (Flyvbjerg, 2006; Thomas, 2015) to highlight that CS has many other applications and reasons for use other than addressing a dilemma (research issue) and finding a resolution for this (Ragin & Becker, 1992). This is particularly the case with qualitative research where studies may be conducted for exploratory, explanatory and descriptive reasons (Yin, 2009), or with purpose for social impact such as change in policy (Macintyre, Chalmers, Horton & Smith, 2001).

Furthermore, CS is now recognised as a practical research methodology, which advocates for in-depth and comprehensive research right from the preparation and planning stages to conducting and analysis stages (Creswell, 2014; Yin, 2009). The implication of the term 'practical' may also vary depending on the paradigm of research. Using CS practically in social sciences may consist of theoretical development and theory testing in unique cases that do not conform to expectations, or with existing knowledge, as it may be a novel occurrence; something left unresearched or misunderstood by previous researchers (Flyvbjerg, 2011; Yin, 2013). One example of this is research by de Visser and Smith (2006) who conducted a single case study on the perceptions and experiences of a 19-year-old man to investigate the links between masculine identity and social behaviour. This study used the experience of one man to describe how men can view themselves in relation to discourses of masculinity, and how these can have critical implications upon their masculine identities and health-related behaviour. In addition, this single CS as able to shed light on the types of barriers surrounding help-seeking and communication about personal male health to bring about change.

Comparatively, within the field of medicine, a pragmatic CS has the potential to save lives and protect public health interests by highlighting new medical cases or concerns with medical practice. In addition, although physician researchers have an interest in their area of expertise or study, most CS are not sought out, but instead brought to them during clinics and emergencies. This contrasts to social science where most researchers formulate research studies out of interest and identification of a gap in knowledge. A recent medical example that demonstrated pragmatic and instrumental use of CS highlighted the poor medical regulation of the use of dermal fillers after a 29-year-old woman attended the eye casualty with vision loss and other symptoms after undergoing a non-surgical rhinoplasty in a private beauty clinic (Jolly, Bhalla, Zakir & Joshi, 2019). This single case study has the impact to prompt changes in the lack of regulation of certain beauty products used in the industry to prevent future patient sight-loss.

Although there is various guidance for CS research, it is the researcher's responsibility to be consistent in their use of the methodology and explicitly describe and demonstrate the guidance they have used so that readers are clear.

3.2.2 Types of Case Study

The concept of the CS in social science research raises many questions about how a case ought to be defined (Stake, 1995; Yin, 2009), how it should be conducted (single, multiple CS) and what criteria or guidance should be followed for CS inquiry (Raggin & Becker, 1992). In order to address these questions, it is necessary to know the type of CS which is to be used to direct the research. Yin (2009) proposed three types of case studies: exploratory, descriptive and explanatory. He argues that what differentiates the categories are when each method is used to suit a research circumstance and not a hierarchy of which type of study is considered better and more complex.

In order to distinguish the use of the types of study in general, three conditions must be addressed in the planning stages of research in order to avoid the 'gross misfit' of a type of study with a research question, when another type could be more appropriate and advantageous (Yin, 2013). Conditions to address are, a) the type of research question, b) the extent of control the researcher has over real behavioural events and lastly, c) the degree of focus on contemporary as opposed to historical events. Answering these questions allows for the relevant type of study for the research to become clear, with further clarification on the type of CS to be adopted (explanatory, descriptive, exploratory, Yin, 2014). In this study, the research question consisted of an amalgamation of inquiry, which included 'how', 'why', 'when' and 'what' in relation to the events reported in Steve's journey and how these were reported. This matched the inductive stance of this study to aid the understanding of the multiple aspects of Steve's journey. In addition, after appraising the research motives, it was clear that the nature of the CS was exploratory, in line with the reasons for inquiry.

Stake (1995) distinguishes two versions of CS: 'intrinsic' and 'instrumental'. An intrinsic CS is defined as having an interest in a piece of research because of the need to learn about a particular case, as opposed to studying it for the benefit of understanding other cases or, solving general or universal problems. Instead, there is an *intrinsic* interest in the CS itself, which is supplemented by its uniqueness. On the other hand, an instrumental CS is associated with using the CS to understand something else or look more broadly at related contexts or circumstances. As such, the inquiry is useful or *instrumental* in accomplishing an understanding of something related or wider social phenomena. I chose an intrinsic CS as the research aimed to understand the uniquely reported experiences of a particular journalist who had access to some of the best cancer treatment in the world and uniquely reported this through a series of radio interviews and diary entries across the media.

Other conceptualisations of CS focus upon the different ways that these can be used to aid theory or real-world problems using the specific context of the case (Creswell & Poth, 2018). For example, the classification of CS (Eckstein, 1975), shows five instructive ways of using case material as explained below. Parallels between these five ways and Stake's (1995) proposed types of CS (intrinsic and instrumental) can be seen. Eckstein's five ways consist of configurative-idiographic, disciplined-configurative, heuristic, plausibility probes and crucial. Due to the nature of my study, I identified it to be a configurative-idiographic CS due to it being unique, exploratory and inductive in nature. Eckstein explains a configurative-idiographic case to be possibly descriptive in nature and reflects the circumstances of events to provide insight into the relationships between elements in the case with an idiographic approach to the context or situation. In addition, it does not easily lead to direct theoretical interpretations or additions due to the uniqueness of the case. Therefore, adopting a configurative-idiographic way is relevant for the study. This is because I could not be sure of the type of findings that would be reached through interpretivism (3.3.2) and an inductive approach due to the CS being a first of its kind within the research context of a journalist's cancer journey shared in the media.

3.2.3 The Flexibility of Case Studies

There are many different ways of conducting a case study and numerous way that can be adopted for analysis (de Vries, 2004). As a result, there is a lack of standardisation in the carrying out of a case study which can prove difficult for a novice researcher like myself. Some methodologists recommend an entirely flexible approach to analysis and the techniques adopted for analysis (Flyvbjerg, 2006), whilst others recommend a rigour and a clear trail of analysis (Houghton, Casey, Shaw & Murphy, 2013).

These different styles of using a CS may be reflected by the different paradigms that adopt the methodology. CS methodology is popular within education research and within social sciences such as sociology, anthropology and psychology (Dul & Hak, 2007; Flyvbjerg, 2006; Merraim, 2009; Sternberg & Williams, 1997). The perspective adopted by each of these research areas may explain why case studies are conducted in different ways to one another. On the other hand, this very notion may demonstrate the fact that a case study is an incredibly flexible and diverse methodology that can use pre-existing theories for guidance or create its own theoretical framework to provide explanations (Baxter & Jack, 2008).

Within CS research, theory can be drawn upon, compared and built upon, which the flexibility of CS analysis freely facilitates. Furthermore, Bourdieu (1992) defines theory as a 'tool' which shouldn't be regarded as an 'endpoint' of inquiry but instead, argues that theory is disposable in research Therefore, I argue that although there may be a lack of standardisation in philosophical guidance and

carrying out of a CS, this appropriately mirrors the concept that each CS is unique and requires to be carried out differently to another, to ensure the in-depth generation of analysis, as emphasised by Yin (2009). One way of doing this is by utilising theory to create the flexibility required to explore a case from different perspectives.

3.2.4 Strengths and Limitations of Case Study

It has been argued that CS methodology provides valuable means of researching social and educational topics that require an idiosyncratic approach (Hodkinson & Hodkinson, 2001). Multiple strengths have been outlined to advocate the effectiveness and valid investigation that CS brings to research. This is because it requires in-depth or rich explanations of issues or worthwhile topics (Flyvbjerg, 2006; Yin, 2013).

Firstly, CS can provide insight into complex inter-relationships. This is done by restricting the scope of the study using case boundaries which aids the construction of a detailed understanding of the specific phenomenon in the specific context that is being studied (Yin, 2013). Studying within these relevantly-set boundaries means that in-depth understanding can be reached, highlighting any complexities that may not necessarily be uncovered in another type of study such as an experimental design or qualitative interview (Yin, 2009). In addition, an in-depth CS facilitates a richer theoretical development, whether that be inductively-developed theory or adding to existing conceptual frameworks (Flyvbjerg, 2006).

Secondly, CS is grounded in lived reality (Hodkinson & Hodkinson, 2001). This is where the research looks at the real-world context, therefore addressing issues and topics that validly represent the experiences of the individual. Implementing a design in a real-world context as opposed to using interview data from a research context, supports the notion of a more valid and robust type of methodology that CS can bring to research (Stake, 1995). A CS can also strengthen qualitative research by guiding the researcher to be comprehensive, holistic and in-depth for the type of social phenomenon under investigation. The methodology emphasises the importance of using multiple sources to ensure extensive and complete collection and analysis of data. Useful CS methodological techniques such as the concept of a bounded system (3.2.6) focuses the scope of the study to relevant data, so that validity of the research is maintained, and this focus allows for in-depth exploration relevant to appropriate aspects of the topic (Yin, 2009).

Thirdly, rigour is a process adopted and built into CS and therefore promotes validity and reliability throughout the research process with strong and standardised guidance for researchers to follow. This contrasts with the less amount of practical guidance for other methodologies such as ethnographic research (Willow, 2010). Techniques such as triangulation (see chapter 4, 4.6.1.1) enhances rigour and

flexibility of a CS, as it is possible to uncover unexpected or unknown angles and perspectives of the topic under investigation. Looking at the research through multiple perspectives not only increases the validity but also provides a better inductive research technique in uncovering real and potentially unaddressed issues relevant to the research question.

The main criticism of CS methodology is that idiosyncratic (unique) or smaller cases cannot be generalised for the benefit of understanding other research phenomena or contexts, and as such to an extent to demonstrate unreliability because of their lack of replicability (Tellis, 1997). Some authors still debate whether it should be classed as a methodology in its own right (Luck, Jackson & Usher, 2006; Thomas, 2015). However, Flyvbjerg (2006) disagrees with this criticism and calls this a 'misunderstanding' of the methodology as this notion depicts that case studies can therefore not contribute to social scientific development or adding new knowledge for the development of a theory. This had been shown not to be the case as major natural and social scientific developments have originated from critical CS research that have impacted our understandings of the world (Flyvbjerg, 2011). In addition, Stake (1995) argued that focusing upon the theorisation and generalisation of research can distract the investigator from important features of the case which may lead to uncover novel and important findings that extend our understanding of a unique topic.

An obvious limitation that I have identified is that certain CS procedures, such as implementing case boundaries, may mean that the CS is crafted to fit the propositions (propositions are discussed later in 3.2.7) of the research knowingly or unknowingly, therefore suggesting that a truly inductive study may not be conducted. Yin (2013) addresses the practical need of case boundaries in order to demonstrate study completeness. Without boundaries, the study may continue for a long time which may be unnecessary, and include other data sources, that although related, do not fit with the general aims of the research. Having an unrestricted study scope would mean that irrelevant factors may be included within the research, making the study lose focus on the general research propositions. It is still possible to set a scope and employ an entirely inductive approach to relevant data collated within the temporal, social, geographic and contextual boundaries set by the researcher for valid exploration of the topic in question (Simons, 2009; Yin, 2009). However, researcher judgement of data and setting boundaries is crucial for study comprehensiveness.

Lastly, as noted by Hodkinson and Hodkinson (2001), CS methodology can be successful in demonstrating the complexities of social issues. On the other hand, it can be difficult to present easily accessible depictions of complex cases that may use multiple types and sources of data and validation techniques. There can be several different procedures to present a set of issues, each of which may be different in its emphasis of the topic used in the CS. However, Yin (2009) also attempts to address

this by providing guidance upon CS report structure (see chapter 4, 4.7), and different techniques to group and later analyse data for cohesive presentation of data (pattern matching, explanation building, time-series analysis, logic models, cross-case synthesis, see chapter 4; 4.5.3).

3.2.5 Rationale for Case Study Methodology

The reason why CS methodology was seen to be the most appropriate approach for the current study was because all analysis consisted of data related to one person (Steve Hewlett), where the aim of the study was to create an in-depth exploration of this individual's experiences and perceptions of their illness. CS methodology allowed for an inductive analytical process derived from a specific context (Yin, 2009), which in this case was the cancer journey of a prominent journalist. As such, newly created knowledge was linked to this specific context, related to this specific individual. The purpose of this case study was exploratory with an interpretative approach using hermeneutics to understand the events reported by an individual and others who were also involved in the journey.

3.2.6 Case Boundaries

Case boundaries act as necessary functions for purposes of clarity about the case study as these demonstrate the extent of sources to be used and analysed within the research (Yin, 2003). Boundaries of the case can comprise of time periods, social groups, organisations, geographical, contextual and defining factors that are related to the study (Stake, 1995 & Yin, 2009). Simons (2009) advocates that boundaries must be set before the case study commences. These boundaries direct the research inquiry to relevant and appropriate data. Simons also recommends that the setting of boundaries before the study begins, can allow for refinement of boundaries later on to reflect any changes in the research during source collation and during the analysis period where other phenomena may deem to be relevant for exploration (Stake, 1995). Therefore, boundaries may require re-evaluation so that they are continually relevant for the study.

The data boundaries that I applied to my research consisted of any data that related to Steve Hewlett's health and cancer journey, including experiences and perceptions of others who were involved in his journey.

3.2.7 Research Propositions

Case propositions are statements which can help to assist in the direction of the research, similar to hypothesis (Yin, 2003). As such, they may provide a foundation and meaning to the research if seen as relevant by the researcher who may already be knowledgeable about the topic (Baxter & Jack, 2008). As well as this Baxter and Jack suggest that propositions have the potential to form a conceptual framework after verification through data analysis. The propositions that I included were as follows:

- Steve Hewlett was influenced by his journalistic background to explore and share his journey of cancer;
- he shared his journey for the benefit of audiences;
- having a media platform facilitated the sharing of information;
- the sharing of experiences was also dependent upon his physical health but not due to successful or unsuccessful treatment.

3.3 Ontology and Epistemology

3.3.1 Ontology: Realism

Realism is a philosophical stance that aims to depict the reality of something (Maxwell, 2012) and in the case of this research, the studied subject, which was Steve Hewlett's reality depicted on radio and in print media, as a person diagnosed and living with advanced OC. There are many versions of realism, which have been added to and refined as philosophy in scientific research has evolved; in order to address the occurring questions from study into human perception and understanding (Archer, Bhaskar, Collier, Lawson & Nourrie, 2013).

A distinct feature of realism is that it is accepted that it is not possible to have objective knowledge of the world as knowledge is dependent upon the factors that influence our ideas and development of knowledge in the first place (Maxwell, 2012). Therefore, we have to deny the notion of objectivity and accept that there are always possible alternate accounts of a phenomenon and the knowledge associated with this (Bhaskar, 2008; Tsoukas, 1989). This creates an understanding towards multiple realities and beliefs associated with these, whether these be objective or subjective. This opposes a radical constructivist stance, that a single reality cannot and does not exist, apart from our constructions of it (Altheide & Johnson, 2011; Maxwell, 2012).

With this perspective in mind, this CS research considers the particular view of an individual (Steve Hewlett) as opposed to a worldview of OC experiences by multiple others, but recognises the relativity of the reality of these experiences. As put by Lakoff (1987, p.164), *the world is the way it is* but arguably, according to the person in question. The CS methodology chosen also helped to shed light on these multiple perspectives of OC by one individual, as I employed multiple data sources and data types (interviews, newspaper diary entries) as well as analysing data from others such as family and friends. In addition, these different data types and sources helped to highlight any differences in the reality of Hewlett's experiences. Therefore, I argue that the ontology of realism widely complements the various aspects used in CS research.

Additionally, it is argued that many of us are 'garden-variety' empirical realists, where we act as if objects in the world (events, objects, people) exist as independent entities from our own experience

with them (Lakoff, 1987). Within realism, it is acknowledged that the meaning given to these objects come about as a result of our experience with them (Maxwell, 2012). Therefore, events, objects and people are philosophically inter-twined and need to be studied within the social context to understand the meaning given to these things. Hence, my study uses the context of the media platform and one man's experiences of cancer to explore meaning of possible concepts such as seeking treatment, health-related identity and purpose of sharing these experiences, which are not independent to the meaning attached to them but instead, only meaningful because of the importance associated with these from the individual's perspective. This leads to the epistemological consideration of interpretivism; an inductive method of gaining knowledge and a type of research that generally aims to understand the perceived meanings from events and experiences.

3.3.2 Epistemology: Interpretivism

Interpretivism is the belief that reality is subjective, multiple and relative (Hudson & Ozanne, 1988). This is reflected to some degree by Maxwell (2012) in the explanation of realism and relativism. Reality is dependent upon perceiving an object or experience in the world and this is dependent upon how we observe and understand matter (Altheide & Johnson, 2011).

The psychosocial paradigm encompasses the acknowledgement of an individual's schema and cognition; their social experiences and the impact of emotions at the time of experiencing an event, all of which contribute to the way that something is interpreted and from which meaning is created (Braun & Clarke, 2006; Smith, Flowers & Larkin, 2009). Interpretivism in this context is particularly useful in the research of human understanding, experience and perceptions.

Parallels can also be observed between realism as an ontology and interpretivism. In the case of 'to be' or to exist (*Dasein* as referred to by Heidegger) and experience means *to be true, to be the case* (Heidegger, 1927, p.32). In effect, this creates actuality in the person's world as this interpretation of feeling and perceiving is core to accessing reality[4] (Inwood, 1997, p.16). This thinking mirrors John Locke's proposed form of empiricism theory from the 17th century, which claimed that knowledge originates from our experience and senses and that mental and logical interpretation of what we observe are the primary tools of coming to a realisation of our world.

In contrast, later in the 17th century, David Hume argued that our senses could not solely be trusted for reliable answers about the reality of the world we live in (Norton, 1981). Therefore, progress in empiricism was made through the use of scientific methods of investigation for unbiased and reliable

[4] This is if we define reality to be a product of a person's social and mental construction which manifests into actuality, not the definition that an independent and objective reality exists outside of human conception or interaction (Lakoff, 1987). Although an objective reality irrespective of a person's perceptions may exist, reality for the individual conforms to their experiences and interactions in their world where meaning and meaning-making are derived from. Thus, making this conceptualisation of reality to be closest to true reality (Hiller, 2016).

answers that could be confirmed after repeating experiments, providing objective evidence irrespective of human senses. Human interpretation through experiences of the five senses and schemata, was therefore viewed as unreliable because of individual differences and multiple constructed realities due to uniqueness of perceived experience. This weakness as depicted in the natural scientific revolution is an inherent strength of interpretative qualitative study upon human understanding and lived experience (Denzin & Lincoln, 1994). This is due to the fact that participant interpretation and meaning-making provides valuable insights into a person's worldview irrespective of whether that view is objective of not. Simple positivist investigation does not take into consideration the breadth of influences upon an individual in their environment and cannot account for or make sense of meaning derived from experiences: an undeniable concept that reflects the complexity of human consciousness and cognition.

There are multiple styles of interpretivist philosophies which include, grounded theory, constructivism, social constructionism, ethnomethodology, hermeneutics, and variations of phenomenology (Hiller, 2016). The chosen form of interpretivism that I have used is hermeneutics (3.3.2.1), which appropriately reflects the goal and nature of the research, which is to uncover the meaning of experiences directly shared by Steve in his reporting. This method of interpretivism was most appropriate as it allowed me to work with pre-existing data, where there was not much in-depth sharing of thoughts and perceptions to be able to carry out deeper analysis of introspection or uncover the essence of an experience without the risk a mis-interpretation. In addition, I was unable to clarify events or Steve's personal thoughts related to these further. A hermeneutic approach allowed me to extract meaning directly from the data that I had access to without having to have an in-depth awareness or familiarity of Steve as a person and his perceptions.

Furthermore, in Heidegger's writings (1927), *Being and Time,* he rejected any proposition that any interpretation of the world is meaningless and contrasted this to the Cartesian model relating to existence, to be incorrectly addressing the similar notion of *Dasein* as environed by present-at-hand subject or object (for example, physical experience). He also juxtaposed the thinking that meaning derived from Dasein, is universal and worldly (Mulhall, 1996).

> *…When something within-the-world is encountered as such, the thing in question already has an involvement which is disclosed in our understanding of the world, and this involvement is something which gets laid out by the interpretation.*

(Heidegger, 1927: translated by Macquarrie & Robinson, 1962 p.190-1)

An experience or event inherently contains some sort of meaning due to its involvement in the world that had naturally occurred in the process of *Dasein* or existence. As a result, this is closely linked with the individual's knowing and perception of the subject (or object). Through discovery and further

interpretation is when these facets of meaning are then brought into the realm of explicit understanding.

And so, an interpretivist epistemology also allowed me to explore Steve's interviews and written works with a purpose of providing an understanding of his reported experiences and what this meant within the wider health, media and public health context. The use of interpretivism was useful for the nature of my data and research for being able to interpret the data for an in-depth exploration and also allowed for me to provide an explanation for what was going on within the context of cancer experience as opposed to identifying a simplified analysis which is what a quantitative piece of research would do (Braun & Clarke, 2014). Braun and Clarke's (2006), approach to qualitative analysis is consistent with the use of interpretivism as it is emphasised that the flexibility of thematic analysis allows for the underpinning of this type of epistemology (see chapter 4, 4.5.4).

3.3.2.1 Hermeneutics

In the lead up to the critical thinking revolution of postmodernism philosophy, Heidegger's propositions around existential interpretivism (phenomenology and hermeneutics) were antecedents to a new way of thought in understanding perceptual reality, later influencing social and psychological investigation of human life and also death (Rainbow & Dreyfus, 1982). This notion of interpretivism inherently advocates that there is no objective reality, and that reason and logic are cognitive and social constructs that lack universal validity. Naturally, this is attributed to the variance in perception, variance in experience, and more importantly, the definitive embodiment of interpretation in events and the environment surrounding one's self in everyday practices, also referred to as hermeneutics (Heidegger, 1927).

The purpose of hermeneutics is to uncover and the meaning of experiences or events that occur, without delving further into deeper interpretation of events or their origins (Rainbow & Dreyfus, 1982). Therefore, the focus lies with the meaning-making of the experience or event itself, as opposed to investigation into the existential meaning or *essence* behind it (phenomenology, Husserl circa 1970, see, Husserl, 2012); or focusing on the event as constructed and perceived by the individual (constructivism). Instead, the focus is upon the meaning derived from the account of the experience and not the origins of the account itself, for example, the meaning of the individual's perception. However, hermeneutics also includes the study of semiotics, which includes metaphor, symbolism and communication (Weinsheimer, 1991), a useful perspective when analysing perceptually-reported events through imagery and creative means such as metaphor. As a result, this type of interpretivism is useful to adopt as a research analytical perspective, where the focus lies with understanding events themselves, irrespective of the way these are reported, for the purposes of a holistic and real understanding of a world-view that directly stems from these experiences (Caputo, 1987). This differs

from a purely realist epistemology, as the tool of Interpretation and the way in which it is utilised to reach contextual meaning, takes the data one step further than mere description of events and experiences (Denzin & Lincoln, 1994).

3.3.2.2 Theoretical and Practical Reasoning for Using Hermeneutics

In order to decide which form of interpretivism would be the best sub-epistemology for me to adopt as the foundation of the analysis, the goal of the research was necessary to consider. This goal being, to understand Steve's journey with cancer, from diagnosis up until death. This mainly included understanding the significance of events and the associated implication of sharing such events. The best way to approach this consideration was to compare whether sub-forms of interpretivism aligned with the goals of my research to ensure the validity of my analysis.

I did not choose to use a constructivist approach as this aims to seek to understand phenomena through the perceptions of the individual and the interaction between their thoughts and their surroundings (Denzin & Lincoln, 2003). I was unable to delve further into Steve's experiences that to clarify his thoughts and process of viewing what he was experiencing at a certain time of the journey. Therefore, I cannot be sure that he perceived things in a certain way in reference to an event. Moreover, Guba and Lincoln (1994, p.110) state that constructivism and its associated research as such: "The investigator and the object of investigation are assumed to be interactively linked so that the findings are literally created as the investigation proceeds." This notion infers that constructivist research is 'transactional' and 'subjectivist', where it is assumed that there is interaction between the researcher and participant where there is opportunity to produce in-depth and clear discussion, which will later help in confident interpretation of findings. However, this interaction, which is primarily lead by the researcher, can influence the findings making these biased towards the goal or interest of the researcher.

Using an epistemological stance of hermeneutics would allow me greater freedom to focus upon understanding the type and the range of experiences that Steve had encountered during the diagnosis, treatment and palliative stages of the cancer and his life. In-depth emotions and perceptions were not discussed by Steve on the media platforms as the purpose of the interviews were to inform audiences of his cancer experience and how to access the best care and treatment possible. The lack of reporting upon sensitive and personal experiences or feelings inherently created a boundary for this research which could not facilitate analysis of Steve's personal construction of his world view. However, plenty of data was available to understand his professional worldview as a journalist; as the cancer journey was both a professional and personal story, it was essential to be able to cover both aspects of his life equally. This is something that hermeneutics allowed through interpretation of both professional and personal experiences, for the extraction of meaning from the

conveyed experiences without the deeper level of interpretation upon Steve as an individual. Although this understanding of Steve as an individual was necessary, this was not heavily required for the purpose of the study.

The relevance of phenomenology to act as the foundation of the research was also considered. This type of epistemology is concerned with the study of lived experiences (Husserl & Heidegger, see Keller, 1999), which goes a step further than natural science investigation, to look not at what something 'is' but instead what prompts an individual to say that something 'is' in the first instance (Giorgi, 1997). Put simply, this type of inquiry does not try to understand the origins of a phenomenon, unlike the natural sciences, but instead tries to understand why an individual questions a phenomenon in the first instance and what meaning (essence) in their existence is created as result. Although a useful outlook to adopt for the analysis of certain experiences such as Steve's initial experience of OC symptoms and the significance of this in seeking help, the function of phenomenology does not align with the type of inductive analysis required to dissect the significant timeline of events shared by Steve.

In comparison, hermeneutics provides the practicality of extracting a more direct meaning from significant events that took place in Steve's journey rather than the deeper level of analysis of the existence of an experience in the first place. Overall, hermeneutics provides the scope to explore both personal and professional cancer-related experiences with the amount and depth of pre-existing data that was available form Steve's journey. I used what was shared within the interviews, interpreting direct meaning from these described experiences, and at times, described methods of journalism (information-finding) as close to literal as possible, as opposed to how he personally constructed his existence, views on society, health and family. This is because this type of data was not wholly available to me or discussed by Steve, the data mainly concerned the sharing cancer experiences. Due to the nature of interpretative research, it was not possible to achieve a universal or indeed an objective analysis of data (see chapter 4, 4.5.5, hermeneutical considerations: the hermeneutical circle, double hermeneutics, researcher bracketing). Therefore, in order to achieve a representation of events that was as close to Steve's reality as possible, only contextual and experiential data available was interpreted without further interpretation of personal perceptions where these were not explicitly shared.

Although it is important and useful to understand Steve's reasons for his perception of the cancer, the aim of the study is focused upon the shared events and experiences themselves, and what can be learned from this. His perceptions, which were framed equally from his personal and journalistic perspective, made it difficult to pinpoint actual bases for how and what he felt, as the majority of Steve's reporting was based on the experiences of the cancer itself and at times, the effect that this

had on him. Analysing the description and explanation of experiences was more reliable, as plenty of this type of data was available, compared to explanations of why he viewed or felt a certain way. There is the possibility that Steve would have chosen not to share sensitive and more personal aspects of the journey within his reporting, which prevents a valid constructivist or phenomenological approach that would help to demonstrate a true reflection of Steve's experiences. Therefore, with the help of hermeneutics and focus on the explicit experiences shared, interpretation of the cancer journey was achieved.

3.4 Epistemological and Philosophical Reflections

I personally believe that there is an objective reality of events that takes place but the way in which a person interprets these is what builds their experience and creates memory of the event. As a result, there must be multiple versions of the 'reality' of an event, which are relative to each other as these are dependent upon multiple people's different perspectives of the same event. I have come to understand that when studying a person's experiences and perceptions in health, their description should be treated as what had occurred, as this reflects their perception and therefore, their reality, and their reality is what is usually being analysed within qualitative research (unless content analysis). This is the main method of accessing people's accounts of experiences and therefore trusting their version of health experiences should be regarded as valid. However, I personally find this to be a challenging aspect in research, as my responsibility as a researcher is to ensure that my observations are accurate reflections of a person's thinking and their reality of events.

I also believe that various factors play a part in a person's interpretation of events and the way that they have experienced or lived something. These factors, in my opinion include, previous experience, level of intelligence, vigilance and awareness of a situation, sensitivity to surroundings and their general personality as an attentive or person. These factors are of course unique to the individual and the individual also has an idiographic way of interpreting things. Therefore, I believe an interpretivist approach to qualitative research is the answer to gaining insight into a person's perspective. Although I believe interpretivism is useful to access a participant's or person's version of events, I personally believe that it is important to be explicit in identifying the level of interpretivism used by the researcher as deeper levels of interpreting data can have implications, such as losing original meaning given to an event by the person and can remove the sense of context in which the experiences were shared.

I felt confident in using a hermeneutical approach for this CS as I did not feel that a deeper and personal level of analysis such as IPA was appropriate. I was unable to clarify or completely understand Steve's personal views about cancer and health. Therefore, I had to make sense of these views through information and experiences that were reported in the media. I did not have the opportunity to

interview Steve and become acquainted with his perceptions as a researcher would normally do in qualitative research, particularly in a CS. Therefore, I also believe that the type of epistemology chosen also depends on the data being used and the details of analysis. After much reading and questioning, it become clear that hermeneutics would provide the appropriate boundary in interpreting Steve's experiences, as these could not be confirmed through methods of member checking (confirming analysis with a participant or person: Shenton, 2004).

3.5 Chapter Summary

In this chapter, I have presented the rationale for conducting a single CS underpinned by an interpretivist (hermeneutic) stance for the benefit of understanding Steve's journey with cancer. The fundamental concepts and techniques (triangulation, case boundaries, time series analysis) of CS methodology were discussed and also applied to the context of the case, along with CS strengths and limitations to understand the breadth of the design and potential barriers to research to be aware of and address accordingly (for example, through reflexivity). With the use of naturally-occurring conversational data, uninfluenced by a research context, it has also been important to acknowledge the strengths of using this type of data and the obstacles that arises with analytic validity as the option to contact Steve for confirmation of the interpretation of significant events was not possible. Chapter four outlines the methods and steps employed to carry out the study.

Chapter Four: Methods

4.1 Introduction

In this chapter, I cover the multiple aspects of the CS analysis and qualitative procedures that I followed. The research was guided by the research question and the aims set to help answer the question. Therefore, a recap of the aims is a useful reminder before the CS are presented. These aims were:

- Explore the different ways in which Steve Hewlett raised awareness about OC, the treatment process and coping with the disease (use of facts, science, policies, official documents, other sources in addition to personal experiences).
- Identify the techniques that were used to do this (psychosocial, journalistic, linguistic, description of personal experiences and perceptions).
- Examine how a journalist's reporting of their own cancer story is different to lay reports in the media.

I address material and the people that I have included within the case analysis, whom I refer to as the 'case members'; I provide a break-down of the case setting, my data collation procedures and how I ensured that I collated all relevant data within the set case boundaries as described in the methodology. An explanation of how I set out to collate the data is also provided, with examples of media (audio and video) sharing platforms and streaming services that I accessed to compare and cross-check originality of the data. After the collation process, I describe the transcription, storage and organisation of this to show how I managed a vast amount of data coherently, to aid analysis techniques such as cross-checking across data sets (Yin, 2009) and triangulation (McGloin, 2008).

I then provide a break-down of the general qualitative steps and thematic analysis (TA) phases that I used to guide my analysis and discussion of findings. This also includes discussion on how I aimed to ensure rigour in the analysis to demonstrate trustworthiness of the CS and to allow readers to be able to make up their own minds about the validity of the research and process that I adopted. As a result, there is further discussion and a recap of hermeneutical considerations such as bracketing and reflexivity that I incorporated during the analysis procedure to guide my outlook and interpretation. This discussion helps to describe analytical influence in the steps that I took to analyse the data which is separate to the technical steps used to guide and organise the research.

There is also a discussion provided on the advantages and disadvantages of using naturalistic data and the difficulties that I faced as a researcher when analysing certain experiences or events discussed by Steve. My decisions to analyse and report the case in a certain style is discussed; this is complemented

by an account of my background, perceptions and understanding is relation to this research, which are all provided within the reflexivity section.

The practical considerations of choosing how to organise and present the CS report are also outlined, with an explanation of the various compositional structures suggested for the type and purpose of a case study. Lastly, ethical points that I considered are elaborated on with reference to using pre-existing data from a known person and the scope and limits of a researcher when using data in this context, derived from the internet.

4.2 Case Members

I refer to people included within the radio interviews, diary entries, video and television interviews as 'case members' as opposed to participants, as within the case study, active data collection was not carried out with participants. Analysis was carried out on existing audio and written texts, which would not constitute the need for active research with participant.

Within analysis I have referred directly to guest titles for clarity and only refer to Steve, and other broadcasters and journalists by their first names. There were different case members across the different sources of data, however the majority of members were present within the PM interviews of whom most were invited guest speakers and experts in healthcare and cancer. Table 2 shows the appearance of members and the amount of time they appear within the PM interviews. Table 3, later on (4.3.1) shows in which interviews guest speakers appear.

Table 2: List of Case Members in Data Sources

PM Interviews	Steve **(22 times)** Eddie **(21 times)** (presenter/interviewer) Carolyn **(twice)** (stand-in presenter for Eddie) Steve's three sons **(twice)** Steve's partner **(once)** General Practitioner **(once)** Macmillan Nurse **(3 times)** Vice President of the Royal College of Radiologists **(once)** Chief Executive of NICE **(once)** Oncologist **(once)** Audience **(phoned-in/wrote-in to PM show throughout)**
BBC Television Interview	Steve Victoria Derbyshire (interviewer)
Royal Television Society Interview	Steve Roger Bolton (interviewer)
The Observer: Diary Entries	Steve

4.2.1 Audience

Audiences existed in the form of listeners, viewers and readers across the different media platforms. This also included audiences who actively engaged with Steve's story to share their own views about Steve's story, share their own experiences with cancer and give their condolences once Steve had passed away. This included phone calls made by members of the public into the PM radio show; live audiences at Steve's interviews or career recognition events; guest comments on website news articles, user comments on video-sharing websites such as YouTube and responses to Steve's writing through social networking sites such as Twitter.

As there were multiple ways that Steve reported his journey, I refer to the amalgamation of listeners, viewers and readers as 'the audience' throughout this chapter and subsequent chapters. This term is also used interchangeably with 'the public' where the impact of the case study upon people is discussed, for example, within the conclusion chapter.

A few audience testaments are presented within the findings, which helped to shed light on listener and reader views, as a third party, outside of the interviews. Although these quotes were helpful in illustrating the potential effects or impact of Steve's reporting, it is important to note that these are speculative statements as the number of testaments that could be found were limited and further context and interviewing would be required of these audience members to gain a collective understanding of the real reflection of the impact that Steve may or may not have had upon the wider audience, such as gaining knowledge and identifying of questionable symptoms.

4.3 Case Setting and Materials

Steve shared his journey on multiple media platforms at the time of being diagnosed and undergoing treatment. These included radio, television and video interviews, written print (newspaper articles) and social media (Twitter). The journey was predominantly shared on air through BBC 4, PM interviews with Eddie Mair usually on a weekly basis, which at first was regularly aired but at times were missed due to Steve experiencing an interim infection, deciding to travel to take a break, or being admitted to hospital. The PM interviews were predominantly used within analysis as this is where the majority of experiences were shared in detail. Table two below shows a timeline of events that occurred in each PM radio interview. The journey was also reported in daily diary entries published through a course of seven articles. Social media posts were also posted by Steve at the time of sharing the journey. Other data from television interviews (4.3.4) were also used to supplement and confirm the interpretation of analysis and strengthen validity of this (4.6).

4.3.1 PM Radio Interviews

A total of 22 PM interviews were aired on Radio 4. In addition to this was a 23-minute tribute segment by Eddie and the show's producer(s), that looked back at some of Steve's memorable quotes, the journey overall and Steve as an individual, as known by Eddie and the team. The first interview was recorded on 19 September 2016 and the last on 13 February 2017, which was then succeeded by two subsequent interviews with Steve's children and his oncologist respectively. Interviews were generally informal, made use of humour whilst discussing serious experiences and were presented in order of the events that occurred. These covered a vast amount of aspects of Steve's journey, health, perceptions, experiences, emotions, wishes, expectations (or lack thereof), reasoning of events, coping and representations of his life. See table 3 for a description of events or discussion covered in each interview.

Table 3: Content of Each PM Interview

Interview	Date recorded	Title of interview and main events reported	Case members
1	19 September 2016	**'Dealing with cancer.'** -Explained the diagnosis (process) of OC that happened in March 2016. -Remembered signs and symptoms and how the these were interpreted but were not acted upon. -Prompted by children to seek medical attention -Routine blood tests taken by GP which was then escalated by the out of hours service as results showed severe anemia. -Endoscopy followed by diagnosis and blood transfusion. -Advice given by Macmillan Nurse on how to take in information during the shock of a diagnosis. -Described chemotherapy (Epirubicin) and dealing with potential side-effects with 'cold cap' treatment.	Steve, Eddie, Macmillan Nurse
2	26 September 2016	**'How to get the right cancer care.'** -Discussed the best care available (The Royal Marsden). -Discussed referral to The Royal Marsden and the delays that occurred with this. -Described experience with the local hospital referral to oncology. -Advice given from Macmillan Nurse (guest) on what type of questions to ask at appointments and how to organise these questions. -Discussion on how to find the right information after a diagnosis.	Steve, Eddie, Macmillan Nurse

3	10 October 2016	**'Next steps on a cancer journey.'** -Previous week's interview missed as Steve went on holiday to Oman. -Pre-chemotherapy checks (blood tests). -Regime of 6 cycles of chemotherapy and scan after three cycles but as the indication that Steve's body was reacting well to treatment, decisions made to treat for eight cycles and scan after four. -However, scans taken at the end of seventh cycle due to certain symptoms which showed cancer progressing. -First line chemotherapy had now failed. Possible reasons for treatment failing were discussed by Steve. -Second-line chemotherapy (Paclitaxel) started to stabilize the cancer, not necessarily for retreat or remission. -First dose of 12 radiotherapy sessions had.	Steve, Eddie
4	17 October 2016	**'How are the Hewlett family dealing with Steve's illness?'** -Radiotherapy as symptomatic relief for the main tumour. -Explained the dilemma of the liver: whether it is possible to not take any drugs and wait for the clinical trials without the cancer in the liver progressing rapidly. -If liver was to be unstable, would then be unable to wait for clinical trials and would have to start second line chemotherapy. -Discussion with Steve and his sons on how they have been coping and their experiences and perceived physical and emotional changes seen in Steve as a person and father.	Steve, Eddie and Steve's three children
5	24 October 2016	**'My Radiotherapy.'** -Had 11 sessions of radiotherapy so far to target the main tumour in the oesophagus for symptomatic relief and improving Steve's ability to eat. However, found it difficult to cope with strong side-effects of treatment. -CT scan taken to decide whether to wait for clinical trials or commence second line chemotherapy (this would rule out any experimental treatment). -Discussed two potential clinical trials available however, four weeks treatment-free was necessary to be able to take part, which could mean that	Steve, Eddie, Macmillan Nurse

		cancer could rapidly progress in that time if still unstable. -Second-line chemotherapy to commence if disease was still unstable as shown by scan. If stable, could afford to wait for the clinical trials for another four weeks (without any treatment). -Teaching the importance of being vigilant about different options and clinical trials available that oncologists might not be aware of if not in their research centre or geographical location. -Consideration of adding a self-funded drug (Ramucirumab) to the second-line chemotherapy (Paclitaxel).	
6	31 October 2016	**<u>'Should I pay for the new drug?'</u>** -Still recovering from the effects of radiotherapy at the time of this interview. -CT scan showed that the cancer was not 'spreading' but was progressing in the liver. Therefore, second-line treatment was to be started urgently and clinical trials were now not an option. -Discussed pricing of the private drug and how this is calculated. -Carried out own research and contacted drug manufacturer directly for confirmation of cost. -It was then found that quote given by private patients' unit provided incorrect quote for Ramucirumab, which was then corrected. -Opted for the addition of drug to improve the chances of extending his life.	Steve, Eddie
7	7 November 2016	**'Dealing with the effects of cancer treatment.'** -Cold cap treatment started again to prevent hair-loss from Paclitaxel. -Experienced more physical symptoms from the combination of residual radiotherapy side-effects and new effects of second-line chemotherapy. -Return of appetite however four stones lost.	Steve, Eddie
8	14 November 2016	**'I've been dehydrating myself for weeks.'** -Meeting with a publisher for the potential of writing a book. -Blood pressure and platelet levels were found to be very low which was explained to possibly be due the effects of Paclitaxel (upon platelets) and Ramucirumab (bleeding). -Admitted to hospital and intravenous fluids administered which helped with Steve's dizziness and extreme fatigue.	Steve, Eddie

		-Realisation of not eating or drinking (especially water) which had contributed to the dehydration. -Avoidance of fluid intake as this made Steve feel sick, raising the question of an intervention needed for dehydration. -Explanation of low platelet levels meant that no treatment was possible. Therefore, more time passing also meant less opportunity for treatment.	
9	21 November 2016	**'I see my condition as a bit of a story.'** -Felt the pressure of time passing and lack of treatment. However, as was hydrated enough, Steve was able to commence chemotherapy again. -Journalist and storyteller in which he felt his positions and openness contrasted other people who feel they cannot talk about cancer. -Sharing thoughts of not feeing 'weighed-down' by the cancer.	Steve, Eddie
10	28 November 2016	**'The intensity of the applause made my spine tingle.'** -Blood tests showed that white blood cells and platelets were down and had to miss treatment again. -Attended a tribute event for his career and contribution to journalism. -Risks associated with attendance which included catching an infection due to a weakened immune system. Advice by Steve's oncologist to keep away from others with a cough or cold and not to use public transport.	Steve, Eddie
11	5 December 2016	**'I discovered there aren't many jokes about cancer.'** -Had to have a platelet transfusion. -Improved liver function and no longer was experiencing major symptoms from the main tumour. -Invited to a Christmas lunch at the local rugby club where Steve wanted to tell a few jokes about cancer to lighten his speech but found no jokes on Google. Read The Royal Marsden's annual report and looked into their reported spending on NHS treatment funded by income from private patients. Questioned the transparency of reporting and vagueness of certain statements. Possible freedom of information request to be submitted for this information. -Planned to visit the Isle of White during Christmas holidays which raised questions of emergency care	Steve, Eddie

		and how to plan for this should his health deteriorate when away.	
12	12 December 2016	**'Once I hit oncology, it was like running into invisible sand.'** -Death of writer AA Gill. His latest article read and discussed which lead to debate on referral times and diagnosis delays, along with Steve's first-hand experiences. -Discussion of funding of drugs recommended by NICE and how decision-making surrounding this occurs. -No funding decision questioned and challenged by Steve directly to the chief executive. -New possibility of clinical trial for immunotherapy (Nivolumab), which was missed by AA Gill.	Steve, Eddie, General Practitioner, Vice President of the Royal College of Radiologists, Chief Executive of NICE
13	22 December 2016	**'My cancer had been rock climbing.'** -A week of the series missed as Steve went on holiday to Dorset. -A recap of the previous episode with NHS guests: *they start speaking NHS.* -Participant criteria for clinical trial was an albumin level of 28 but Steve's was 26, therefore was unable to be consented onto the trial which left him disappointed. -However, another clinical trial was available where a 'wash-out' period was not necessary, which lead to Steve considering his treatment options.	Steve, Eddie
14	2 January 2017	**'I got to A&E before the New Year's Eve deluge.'** -Experienced symptoms of second-line chemotherapy (fatigue, splitting nails, extremely dry mouth, discomfort after eating, unable to taste food, unstable appetite). -Felt that side-effects were a small price to pay if treatment was working. -Felt of pressure, tightness and discomfort in chest at which Steve was then told to call 999 by the cancer team at The Royal Marsden. -Tests were carried out to see whether he had suffered a heart attack and this was confirmed not to be the case.	Steve, Eddie
		'Steve Hewlett on his fears about losing his drug trial place.' -Admitted to hospital and interview was conducted over the phone whilst Steve was on the ward.	

15	9 January 2017	-Latest scan showed that tumour was stable but not in retreat and therefore he was able to be consented on the clinical trial. -Had an endoscopy as new biopsies were required for the clinical trial. -Felt unwell even though this was the last batch of chemotherapy, where he was experiencing sever chills. -As a result, had to go to a local accident and emergency department as advised by his care team at The Royal Marsden. -Given antibiotics for an infection but showed signs of sepsis. -Diagnosed with lower left lung pneumonia.	Steve, Carolyn (filling in for Eddie)
16	16 January 2017	**I'm a victim of Sod's Law.'** -Steve was discharged from the hospital and although thankful for the great care was unimpressed with the length of time taken to be discharged. -As strong antibiotics were taken, probiotics were needed for his stomach. -Clinical trial had been delayed as a result of illness but the aim was to start the trial within a few days. -Reflection of the different obstacles that Steve faced in treatment.	Steve, Carolyn (filling in for Eddie)
17	23 January 2017	**'All I could do was cry, I was so overwhelmed.'** -Researchers had to decide whether Steve could still participate in the clinical trial even though he was consented prior to hospital admission. -However, he was then accepted on to the clinical trial (immunotherapy) in which he was happy but overwhelmed about as he was not expecting to be accepted. -Disadvantage of the therapy was discussed, with the main being that it would not be possible to tell quick enough if the immunotherapy is working. This could then mean that the tumour may grow in the meantime, leaving no other options for treatment.	Steve, Eddie
18	1 February 2017	**'Steve Hewlett says he's continuing with the trial despite his liver misbehaving.'** -Eddie visited Steve at The Royal Marsden -Steve was finding that his appetite and taste were returning after having been on Ramucirumab. -Had an episode where he felt discomfort in his stomach and took painkillers for this. He then ended	Steve, Eddie

		up feeling sick, vomited (red in colour) and was salivating excessively. -Underwent another endoscopy to identify the origin of the bleed. A possibility that the liver was becoming worse was seen. -Unsure whether the immunotherapy would work on the liver and if still continued, care team would be unable to see how far the liver metastases would have progressed.	
19	6 February 2017	**'I was told that I have weeks, possibly months.'** -Still in hospital at the time (The Royal Marsden). -Liver now 'uncontrollable' therefore more treatment of any form not possible, meaning that Steve did not have much time left to live as informed by his oncologist. -Re-introduced to the palliative care team. -Plans to marry his long-term partner put into action. -Marriage took place on the ward, organised at the last minute by the hospital.	Steve, Eddie
20	13 February 2017	**How do you live every day as if it's your last?** -Discussion of palliative care and facilities. -Possible hospice care with current living situation. -Preference to stay at home but this was dependent upon the state of Steve's liver. -Explaining the issues that arise with potentially dying at any time. -Conversation about the usefulness of a 'bucket list' and meaning at the end-of-life.	Steve, Eddie
21	2017 (specific date unknown)	**Steve Hewlett's doctor describes caring for him** Discussion about Steve as a patient and oncologist's views and general facts about dealing with OC.	Eddie, Oncologist
22	12 June 2017	**Steve Hewlett's sons on moving forward** Steve's children discussing their progress and Steve's legacy with academic scholarship.	Steve's three children

4.3.1.2 Nature of the PM Show interviews

Understanding the nature of Steve's radio interviews was helpful in providing context to the way in which he presented and shared his journey. Although most interviews were conducted with solely Steve and Eddie, some interviews included invited guest speakers or interviewees with a purpose of explaining, clarifying and answering cancer coping, treatment and treatment funding-related questions. It was at these times that Eddie provided Steve the opportunity to take over the interviews with his journalistic and enquiring skills to gain information about cancer healthcare. The discussions between Steve and guests were not only prompted for the benefit of Steve's personal interest in his

health but acted as sign-posting and general cancer-related information for the audience. With guests such as a general practitioner, cancer nurse specialist and an NHS chief executive, the interviews discussed different angles of the same types of issues in cancer care, such as waiting times and treatment.

Contrastingly, although audiences had the opportunity to listen to Steve as a journalist and broadcaster, this was supplemented by his journey as a patient, where he shared at times raw and distressing (emotionally and physically) personal experiences. His personal and professional viewpoints aided the direction of reporting the journey and the type of events that he chose to report on. This was also facilitated by Eddie's questioning, particularly towards the end of the interviews when Steve was prescribed opioid medication for pain and this had affected his memory at times.

The cordial and humour-packed relationship that Eddie and Steve shared on air was also influential upon the weekly reporting and helped to lighten the atmosphere when discussing Steve's set-backs and unsuccessful treatments, and in general conversation. An example of this is was when Steve had lost weight due to the tumour progression:

> S*: Everyone always says you know you're looking so well you know, I think yes there's a reason for that.*
>
> E*:* [Laughs]
>
> S*:* [Laughs] *Sort of wish I wasn't really.*
>
> (Int:6)

Another example of humour used to pierce the seriousness of the topic discussed was when Steve shared his experiences of the effects of the growing tumour:

> S*:* [It's] *getting to the point where I go to the lavatory and start spitting and salivating. It actually made me feel sick…. When that happened, if I think too hard about those foods that did that, even now-*
>
> E*: Ok, let's not then.*
>
> S*: No, no then it will make me feel queasy.*
>
> E: *You're sitting too close-*
>
> S*: Haha.*
>
> E*: You're sitting too close to me to risk any danger.*
>
> S*: It's all very well controlled, Eddie of course.*
>
> (Int: 6)

The use of humour in the context of sharing the type of uncomfortable symptoms experiences during cancer, was a useful technique in itself to ease the audience in to listening to the physical and sensitive experiences that Steve shared. These extracts were useful to be aware of during the analysis process to understand the effect that Eddie and Steve's rapport and dialogue had on Steve's reporting. These types of quotes are not discussed within the findings, as the main focus lay with the events themselves and Steve's perceptions, judgements and educating audiences about his journey. To aid my understanding of context and the extent of interviewer-interviewee relationship, a shallow thematic analysis (TA) was conducted within NVivo, which depicted humour as a predominant node and indicator of the type of communication and mutual understanding that the two individuals shared.

Eddie, although informal with Steve, allowed him to take-over and professionally lead the interview to discuss topics of his own choices that were relevant to him as the OC patient. As Steve was a broadcaster with a vast amount of experience in interviewing people, the transition from guest or interviewee of the show to interviewer was succinctly facilitated by Eddie; giving him the platform and time to ask important questions to those 'in charge'. This was seen during interviews where guests working in healthcare (such as the vice president for clinical oncology at the Royal College of Radiologists) were invited to share their policy knowledge and professional experiences of the healthcare system:

> VP*: There is a lack of access to those new technologies within the country. And then you come to chemotherapy drugs that are usually used to prolong life rather than necessarily cure the disease. We have less access to certain drugs than other European countries.*
>
> E*: Steve wants a word.*
>
> S*: Well I- Hi Janette it's Steve Hewlett here.*
>
> J*: Hello.*
>
> S*: My experience was, at the kind of early if you like acute phase-*
>
> (Int.12)

As Steve became more knowledgeable and familiar with the clinical aspects of his health and treatment, Eddie's prompts acted as useful reminders to Steve to explain or recap medical concepts for the benefit of the audience. Although Steve's journey could have easily been shared on air as a self-report, the impact of being interviewed by Eddie created valuable discussions and questioning on audience's behalf, who may not have been so familiar with cancer treatment options or with cancer

at all. This is evidenced by audience members' reactions of having called and written-in to the show to share their appreciation of Steve's weekly reports. (such as a surgeon from a local hospital).

> *Quite a few of my department and outside listen to Steve er on PM. Erm and and we've all been really impressed with what he's been talking about oesophageal cancer. We're pleased that people are prepared to talk about cancer and prepared to talk about oesophageal cancer in particular. Er we deal with the disease that is the fastest growing disease in the UK. And we have the highest incidence in the UK, yet no one knows about it. And Steve taking so well, so openly, so honestly really helps us get our message out that we need to do better and we can do better for this disease. So really, we're really pleased that Steve's talking about it.* (Su: Int. 13).

4.3.2 The Guardian Diary Entries

Seven, mostly consecutive columns, were released in The Guardian Sunday newspaper, The Observer. These contained multiple diary entries, which started from 15 November 2016 to 19 January 2017. A total of 33 diary entries were published across the span of the seven articles with an average of 100 words in each entry, briefly describing the events that took place during the treatment phases and Steve's perceptions and feelings associated with these experiences. These extracts provided Steve with a platform in written media during his cancer to be concise yet creative in reporting his interactions with various people and the healthcare system process along the journey. The diaries did not start until the eighth PM radio interview had been aired, therefore content covered within these consisted mainly of treatment experiences.

Although the diaries were a different mode of reporting, the content of these weekly segments mirrored the information shared on the PM radio interviews. As such, the daily diaries were condensed versions of the experiences discussed on air with Eddie Mair and provided a brief summary of events in a chronological order. The dates of each entry provided a description of the micro-events that led up to each significant treatment phase (chemotherapy, radiotherapy, experimental treatment). Reporting through the diary entries was narrative and included a few brief self-reflections of the experiences and perceptions towards events and news encountered for the day. This style of writing provided a sense of talking directly to audiences which was a contrast to the way information was shared within the radio interviews, which consisted of Steve talking to Eddie in a conversational manner, in the context of informal interview and somewhat podcast fashion.

4.3.3 Social Media

Steve promoted his PM radio interviews and The Guardian diary entries with 're-tweets' and posts through his personal Twitter account. This helped to showcase his written works and reports in order

to raise awareness of oesophageal cancer-related experience. Website links to associated information such as petitions to improve warning labels on over-the-counter heartburn medication were also posted to support and raise awareness of this matter. The information shared through social media was incremental to reaching other types of audiences who may not access Radio 4 or The Guardian.

4.3.4 Other Television and Video interviews

Interview with Victoria Derbyshire

Steve was also invited to talk about his diagnosis on the Victoria Derbyshire (VD) Show on the television channel BBC 2, with Victoria Derbyshire who had been diagnosed with breast cancer in 2015. The 20-minute segment on the VD show provided a brief-overview of initial symptoms, experience of chemotherapy, radiotherapy as well as discussion on the unpredictability of the Steve's remaining life.

The interview first and foremostly explored the reason as to why Steve was being open about his cancer diagnosis and was transparently sharing this on air, to which Steve explained that after sharing his diagnosis immediately with friends and family, they felt 'part of it' and this led him to reflect on the potential usefulness and purpose of sharing his journey:

> *It empowered them* [family] *actually… they felt part of it. That sort of led me to I think to wondering about whether people really talked about cancer enough… if you listen to a lot of Radio 4, quite a lot of it's about cancer* [laughs] *funnily enough. But it tends to not be men talking about it. And I don't mean people are sort of closed about their feelings about it but it tends to, it doesn't- there's something about what we've done with PM which appears to have touched something of a nerve. And I could only speculate as to kind of what that is but I sort of thought, there's not enough said about cancer often enough.* (S: Int. VD).

Interview with Roger Bolton

Another interview that Steve took part in was held at the BBC Radio Theatre in November 2016 with Roger Bolton in the presence of a live audience. This interview elaborated on how the idea and decision to document his experiences originated from discussion with Gwyneth Williams (Controller of Radio 4). After sharing his reflections on what radio show to select to share his initial diary segments, Steve shared his views on choosing Eddie Mair's show as the most suitable platform:

> *I sort of thought well the thing about Eddie's if he, if we started doing this and he liked it, then he's defend it, he'd protect it. And so you know, editors will come and go, producers will come and go, but Eddie is a rock upon which that programme is built.* (S: Int. RB).

4.4 Data Collation

I refer to having collated data as opposed to having actively collecting the data through facilitating data generation through research interviews. Collecting data involves the notion that the researcher has actively generated the data through participating in a research behaviour (interviewing, surveying, handing-out questionnaires). I did not collect data as such and had instead collated the relevant data for the research, in line with the case boundaries, to ensure proper and relevant data inclusion.

The study was retrospective in nature, which aimed to analyse experiences already documented by Steve. As I was looking at the time-frame of Steve's journey itself, I decided there was no additional data collection that I needed to undertake due to there being rich and a large amount of pre-existing data. The existing material provided scope to meet the research objectives and confirm or refute the research propositions. This was determined when collating all of the data and conducting an initial shallow analysis with memo writing and coding (general qualitative analysis, step one; thematic analysis, phase one, see 4.5.2 & 4.5.4 respectively). This determined whether more data was required or not to be able to answer the research question sufficiently.

4.4.1 Use of Pre-existing (Naturalistic) Data

Data used within the CS consisted of pre-existing material, all of which was freely available on the internet. There can be both advantages and disadvantages to using pre-existing data that has occurred as a result of natural human interaction outside of a research context. A main advantage involves the inherent validity present as a result of using this type of naturally-occurring data. According to Guba (1981), a criterion to ensure 'trustworthiness' of data used within research is its 'neutrality'. This refers to data generation which has not been influenced by the researcher. For example, through the use of closed or leading questions within a semi-structured interview or indeed through the use of planned questions, which directly relate to the researcher's agenda and proposed research questions (Krefting, 1991). Instead, 'neutrality' occurs when the data is unbiased to the agenda of the research and truly allows for inductive analysis. Additionally, the neutrality of pre-existing data allows for a valid reflection of real-life occurrences, which can then be accessed and qualitatively-studied within a real-world context (Jupp, 2006).

Although Steve's interviews were carried out by other journalists and broadcasters, any biases that may have influenced Steve's thinking or answers were separate to the rationale of the CS research. The neutrality that exists in pre-existing data echoes the advantage of using such data as it is unbiased from any directive questions that a researcher may ask in a typical qualitative interview, therefore showing that the data is true to the context under investigation (Cristancho, Goldszmidt, Lingard & Watling, 2018). In addition, all interviews and diaries were documented in the media, which was a real-world context, helping to facilitate more realistic answers that reflected the goal of the story-

telling that was to raise awareness of OC. Had I interviewed Steve, the interview would not serve the same function as his reporting in the media, which was done for the benefit of the audience as opposed to meeting an academic research purpose.

One disadvantage of using pre-existing data is that it does not have the same benefit that a research interview would have. If I had the opportunity to interview Steve, he may have been more likely to share his views and experiences within a research interview that maybe he would be unable to share on air, such as more personal experiences. However, this would be the case if the interview remained anonymous thus allowing him as a participant to share thoughts unrestrictive and without being judged by an audience.

This leads to another disadvantage of using pre-existing data in the CS, which was that I was unable to ask Steve for further explanations or clarification about certain information shared in the PM interviews (see reflexivity for reflections on this issue). This meant that significant events and perceptions were not explored in-depth or prompted by the interviewer from which the CS analysis would have benefited from to strengthen and aid more accurate interpretation of events. Therefore, at times, using pre-existing data is not as comprehensive or in-depth in content as a professional research interview can be.

In addition, with the use of pre-existing data, it was necessary to work retrospectively in setting and applying case boundaries to the data. This differed from the traditional setting of case boundaries carried out during data collection (Yin, 2009). However even with prospective data collection, boundaries are still used to guide the use of the data, and so to an extent, there was not a significant difference in the application of boundaries to identify relevant use of data.

Other pre-existing data from Steve's annual memorial lectures, post-death news and tributes were not used for analysis as much of the information was shared by him in the diaries and interviews, which had a more direct impact upon audiences at the time of his cancer. News coverage after Steve's death was a useful recap for the public about his journey, however this information did not enhance the personal experiences that he originally reported. Therefore, this type of data was not used as I found these to be brief summaries of the journey that did not add to the analysis process.

It is also important to note that print data, such as Steve's diary entries from The Observer (The Guardian), may have been subjected to journalistic editing, which could mean that this affected the reporting of certain experiences or the way that certain views were shared. This was taken into consideration when interpreting data. In contrast to this, the majority of Steve's interviews were recorded live and exposed verbal clues about Steve's hesitance or willingness to speak about something. Such clues included pauses, verbal back-channeling and tone of voice (excited; somber)

which also demonstrated contemplation and at times, candid reactions which provide a clearer image of events and allowed for better interpretation.

4.4.2 Data Searching and Sources

Yin (2003) recommends that having a research protocol guides data collection, which can also include potential ways of implementing triangulation techniques such as using multiple data sources to support subsequent data analysis (Carter, Bryant-Lukosius, Dicenso, Blythe & Neville, 2014). However, it is advised that this protocol should be robust and planned well to ensure valid exploration of relevant data that has the potential to be used in addressing the research in question (Yin, 2003). As I did not collect data myself, my planned protocol involved the collation of pre-existing data. During the preparation and planning stages, I built my first impression of the type and content of data through initial searching and reading by using search engines. Once formal data searching was carried out, initial impressions of the data were replaced by better understanding and awareness of the data, which is noted to be the case by Stake (1995). Once the analysis process has started, this awareness was further developed where I had an even better understanding of the data and Steve's journey as a whole. Although, I had a protocol in place for the collation of data, this was added to and revised during the initial shallow search for contextual data.

4.4.2.1 Search Strategy

To ensure that the data collation was valid, I firstly employed the use of the set case boundaries to guide the scope and relevance of the search (Yin, 2009) and secondly, I looked at multiple sources and types of data so that I could use these for triangulation (4.6.1.1) as well as interpretation during analysis (Guba, 1981; Shenton, 2004)

The first step carried out was by using selective search words and a combination of these words to yield articles, videos and audio interviews regarding Steve's reporting of cancer across multiple search platforms. Some examples included: 'Steve', 'Hewlett', 'cancer', 'oncolog*' 'oesophag*', esophag*, 'diagnos*', 'story', 'sharing', 'reporting'. As there is an entertainer by the same name, I conducted advanced searches, also with the use of Boolean phrases to refine searches and make these more relevant to the CS. An example of this included 'Steve Hewlett oesophageal cancer' NOT 'comedian' or 'ventriloquist'[5].

I searched through various media sources and streaming and, podcast services to ensure that I had conducted a comprehensive search. When searching for the PM interviews, I cross-checked each interview uploaded onto each website or streaming service so that I was sure all interviews were the

[5] There is another individual by the same name in the entertainment industry who is a comedian and ventriloquist.

same versions and the same duration so that I did not miss any other vital reporting from the interviews. In addition, I conducted this step as I wanted to be sure that there were not two different versions of an interview: an edited version and unedited version which happened to be available to the public. However, as most interviews were live, this was not the case. As a result, all interviews irrespective of what media site or steaming service I was able to listen to or download these from, were the same.

To search for the interviews that Steve had participated in after diagnosis, I searched the BBC website and radio archives, the YouTube website, Apple iTunes and podcasts and, the repository of Box of Broadcasting (BOB), which is available for educational purposes through DMU. Phrase and word searches were as broad as possible but still in line with the context of Steve's interviews and diaries (as noted in my initial shallow search of data). This was done to ensure that I did not miss possible titles of any uncovered interviews in the search.

4.4.3 Data Storage and Organisation

After collating the data, all audio and video interviews were transcribed verbatim and saved as Microsoft Word documents. Diary entries and other website articles were downloaded or 'screenshot' and saved onto separate Word documents. All data was then imported in to NVivo, also known as computer assisted qualitative analysis software (CAQDAS, Creswell & Poth, 2018, p.210; Davidson & di Gregorio, 2011, p.628). Each transcript, diary entry and article was imported as a 'source', allowing for rapid identification of each type of data set. This also allowed for easy retrieval of quotes and annotations made using the software.

In addition, 'nodes' were created through grouping certain text from different data subsets, which categorised the selected data under labeled nodes. Nodes created a method of organising noteworthy quotes and tracking digital annotations from different data sources. As echoed by Davidson and di Gregorio (2011), the idea of CAQDAS is to help to organise data in layers to which first includes initial organisation of the imported subsets of data. Other levels progress the organisation once data is explored interrogated and interpreted. However, this is dependent upon whether the researcher uses the CAQDAS as the main and only means of analysis. I used NVivo to help organise the vast amount of data that I had collated and transcribed and to produce a shallow analysis using the query functions (4.5.2) to support manual analysis carried out. Therefore, the organisation of data was an ongoing process in which organisation became more refined during the research, as changes were made to the labelling of nodes and categorised quotes. As analysis advanced, the digital organisation of data was updated to reflect this.

4.5 Data Analysis

4.5.1 Qualitative Research and Case Study

Qualitative analysis in case studies can be challenging because of the flexibility of the methodology, where not much guidance has been developed for CS as a methodology (Yin, 2003). In addition, the data that can be collected or collated for a CS can be a vast amount, therefore it is up to the researcher to generate a research-worthy question, propositions and case boundaries to allow for systematic exploration of concepts and themes (Richards & Morse, 2013). Data should then be skillfully analysed through interpretation as close to the reality of the events and experiences demonstrated by the case (Yin, 2009). Furthermore, Denzin and Lincoln (1994, p.500) reminds researchers, "there is only interpretation, nothing speaks for itself". This implies that interpretation is an inescapable, yet instrumental process to understanding qualitative data and so it is the researcher's responsibility to undertake analysis from a knowledgeable perspective to avoid misinterpretation and non-credible analysis. Braun and Clarke (2006) explain that one way of ensuring this is to follow the process of familiarising one's self with the data to be able to produce an informed discussion of the findings (4.5.4). To analyse the data, I chose to utilise guidance from two qualitative methods: Creswell's (2014) general procedures of analysis and Braun and Clarke's recommended phases for thematic analysis (TA). Below I provide descriptions of the steps or phases involved in each of the methods with explanations of how I implemented these (or not, if the case).

4.5.2 General Procedure of Qualitative Analysis

Creswell (2014) proposes the use of a general procedure (figure 3) to follow in qualitative inquiry, in which the steps of a specific research analysis strategy, in this case, case study-specific and TA steps are blended within this procedure or vice versa. As a result, researchers are urged to involve multiple levels of analysis with the use of general and specific analytical procedures.

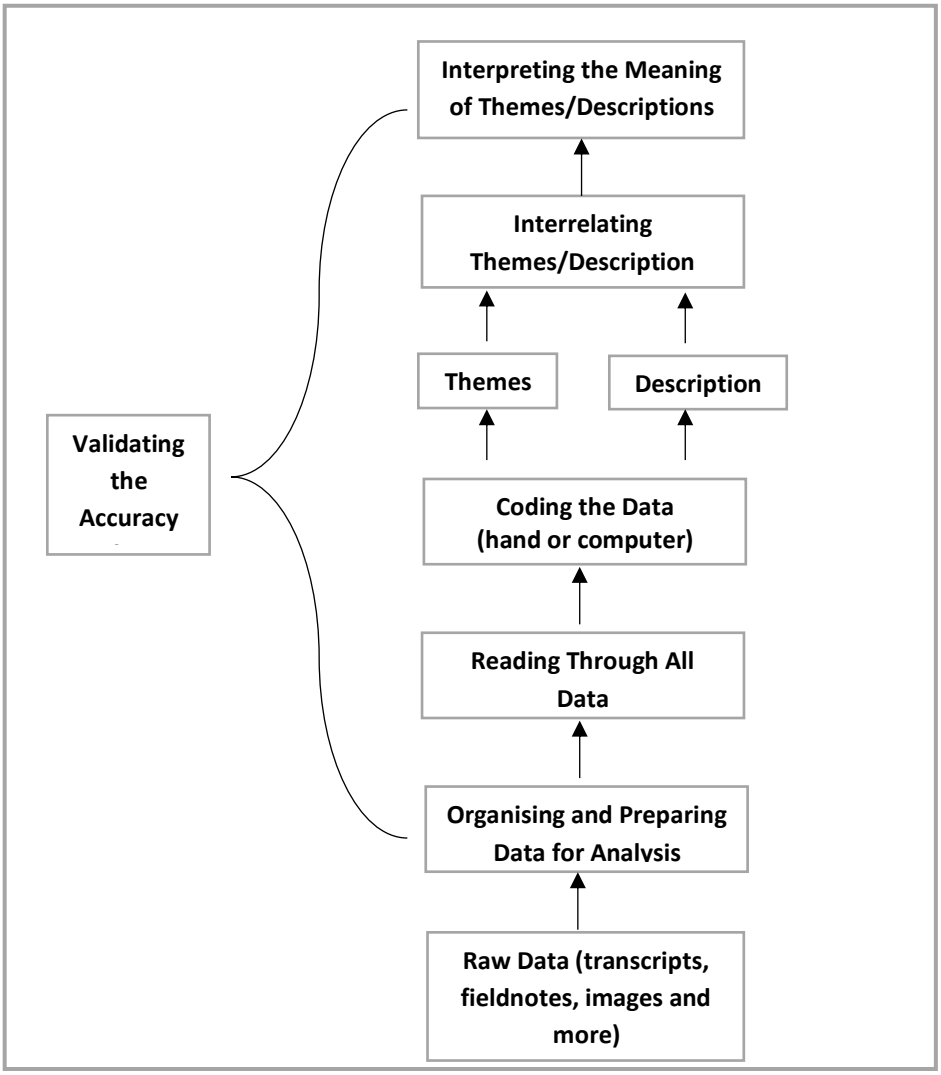
In order to aid my coding of data by hand and digitally through NVivo, I followed Creswell's (2014) steps to help guide the organisation and order of conducting these procedures. This was also used to guide my initial descriptive analysis of Steve's journey to gain familiarity with the data and potential future points that I wished to focus with TA that could be relevant to discuss in relation to theory and current concepts within health and media. As a result, I was able to build an understanding of the direction of the analysis in relation to the initial prominent findings, as opposed to delving into analysis without having a general plan. I was able to confidently move on to a deeper and comprehensive level of analysis by using Braun and Clarke's (2006) six phases, which allowed me to utilise my interpretivist stance to create a conceptual understanding of the events shared, and show how these related to wider health and social theory, and the current psychosocial understandings of health awareness and personal experiences with OC.

There are visible parallels between Creswell's (2014) and Braun and Clarke's (2006) qualitative guidance with the ways in which it is suggested that the researcher familiarises themselves with their data and carries out initial or superficial notes and memos to build general and contextual understanding. However, TA then provides a standardised analytic procedure to facilitate generation specifically of themes that are reflective of the research question and inductive analysis (as used in this case study). In comparison, Creswell's guidance is a helpful set of practical steps to organise the process of analysis, irrespective of the study's chosen epistemology, which is instrumental to producing a good TA. Creswell encourages critical thinking of the overall meaning of the data early on to ground the researcher in focusing on meaningful analysis that tells something about the phenomenon under study.

Validation of the information collected and analysed is also an incorporated step in Creswell's guidance, which prompts the researcher to ensure consideration of the criticalness and rigour of certain aspects of the research. Hence, the use of an additional general analysis model to TA, helped with multi-level analysis (descriptive and interpretivist) and also helped to provide the practical considerations such as validation to enhance qualitative study. This is something that TA does not currently focus upon within its guidance. This aspect had therefore influenced my decision to use Creswell's model as it covered certain areas that TA does not explicitly promote in its method of analysis. This may be the case because TA's focus is solely upon developing themes to demonstrate an understanding of the concept studied. In addition, Creswell's model also draws parallels with CS research, which encourages validation techniques such as triangulation (source and theory). This reinforced another reason as to why I found it beneficial to use Creswell's steps as practical guidance when beginning to organise and analyse the data.

Below I provide an outline of all Creswell's (2014) six steps and an explanation of how I implemented or took influence from these to inform my organisational and analytical approach to the data. I found steps one to five useful for the technical and practical analysis of the CS and step six useful for critical analysis. When referring to the processes, I distinguish between Creswell's and Braun and Clarke's (2006) guidance through the use of 'steps' and 'phases' respectively.

Figure 3: Data Analysis in Qualitative Research (Creswell, 2014)



Step One

Preparation and organisation for data analysis. Processes such as transcribing, visually scanning the material, typing written field or initial notes, arranging data into different types and highlighting the different sources and their origins. This step mirrors some aspects of phase one in TA.

Step Two

Reading and looking at the data. The researcher should reflect upon the overall meaning of the data which should encompass thoughts such as what ideas are participants sharing? What overall impression of 'depth', 'credibility' and 'tone' is seen? General thoughts and, or observational notes can be scribed in the margins of transcripts (manually or digitally).

After transcribing all interviews (video and audio) and importing print data (newspaper articles written by Steve) into NVivo, any initial noteworthy thoughts, ideas and shallow analysis were written up as annotations alongside the texts (also known as 'sources' in NVivo) (appendix 1). These annotations

acted as prompts for later, in-depth analysis when I became more familiar with the data, context and Steve's stated reasons for sharing his story, which allowed me to expand upon or reject these points from a more informed and analytical perspective when referring to literature.

Step Three

Beginning to code all of the data. Coding is carried out by organising the data into chunks and using a word or title to represent a potential category. Where relevant, as it captures important findings, some coding categories can be labeled with the actual language used by a participant (an in vivo term). Some examples of code categories that can be developed are, codes on topics, codes that are surprising codes and codes that are unusual. These types of categories should therefore be able to show the researcher where unexpected or unique findings are seen within the data, which can then be drawn upon when the discussion is written. Codes should be developed on the basis of information collected and analysed from participants or studied text (inductive approach). Predetermined codes can also be used if a structured interview schedule has been used, where it is known that certain topics have been intentionally focused upon, or where the researcher is looking to analyse only certain aspects of a concepts due to an obvious gap in research.

Although in vivo terms are useful to encapsulate coding, I did not use these at this stage of general analysis as I used generic terms based on Steve's thoughts and perceptions, and the events that took place. These acted as the foundation for further analysis later on when conducting thematic analysis and providing major themes with concrete titles with in vivo names that reflected the significant events that occurred in the cancer journey (4.5.4: phase 5).

Step Four

The coding process is used to create descriptions of the research setting or participants, and themes for analysis. Codes can also be developed for such descriptions, which are useful in certain research contexts such as developing detailed descriptive case studies. The coding is used to generate a small number of themes (five to seven) which are then used as the major headings in the qualitative study. Ideally, these should represent multiple perspectives from the individual(s) studied; the setting and noteworthy social concepts or phenomena, supported by relevant evidence such as quotations.

I used certain aspects from this step alongside the TA phase of 'reviewing themes'. As a result of following step four, I was mindful to include theme headings that reflected the different stages of the cancer journey and the various types of experiences and aspects covered by Steve (physical health, psychosocial effects of the cancer, social use of language and research and reporting techniques used to cumulate information for the benefit of audiences). Likewise, I was also able to find multiple

appropriate in vivo terms that acted as the sub-themes' headings which usefully related back to the main themes and the order of the journey.

Step Five

Description of concepts, and themes should then be advanced. The most popular way of doing this is through narrative analysis to convey findings. This can also include a chronology of events. Tables and visual aids may be used to supplement the written description provided.

At certain stages of writing up my analysis, particularly at the beginning of an introduction of a sub-theme, I used narrative analysis to provide additional context to the reader. This was done as the many events that took place in Steve's journey would have been difficult to include in the discussion without the finding and discussion chapter becoming a purely descriptive account of the journey. Therefore, narrative analysis was conducted where I felt that readers would require or benefit from prior description and dissection of events before being able to understand a discussion of a significant experience or segment of the journey.

Step Six

The final step involves the interpretation of the findings or results. Applying a critical lens to understand what are the lessons that can be learnt from the research must be done as it is vital to capture meaning derived from the interpretation of the findings. A comparison of the information learned can then be confirmed or denied against the literature and relevant theory. The interpretation can also lead to new questions that arise as a result of novel findings, where it would be beneficial to gain more insight into these to potentially further explain the novel findings of the current research.

This step was very helpful for me when considering the implications of the analysis and findings and, its relevance to future research required. However, my interpretation of the data began straight after the initial note-making and descriptive codes (step three), as I began to become more familiar and confident with understanding each event in the journey. I began to code under titles, as per phase two (Braun & Clarke, 2006), that captured my understanding of how Steve presented an event or shared his views. As a result, interpretation was the driving force of the analysis from the early stages of the qualitative process. This was the case for two main reasons.

Firstly, TA guided the stages of my analysis more so than Creswell's (2014) general guidance. However, the general steps echoed by Creswell helped with the organisation and narration of Steve's journey. Although events were shared chronologically as Steve's journey unfolded, there were thoughts and feelings shared which were retrospective and this data was relevant to segments shared very earlier on, such as looking back at diagnosis experience. Therefore, the organisation and presentation of the journey was transposed according to the way in which I felt was the best order to present both the

personal experiences and journalistic lens, as these aspects went hand in hand throughout the story. And so, Creswell's steps helped me to adopt the descriptive approach that I required to formally bring the various events of the journey together. However, TA modeled the analytical phases that I required for guidance to interpret the significant experiences and time-points of the journey.

Secondly, it was important for my selection of interpretivist epistemology to facilitate the direction of analysis from an earlier stage, as from my reflections during and after the transcription of interviews, I became aware that my knowledge of health psychology and personal perceptions of Steve and OC were playing a crucial role in the way I understood his presentation of events and experiences of dealing with a major illness. Therefore, I would argue that a shallow level of interpretation occurred even when building a description of the various aspects of the journey, particularly during step two and phase one of my analysis (familiarising myself with the data). It is argued that most qualitative analysis is effectively an interpretation of the data, which occurs at different levels, consequently transforming the data by which researcher aims to create intelligible accounts (Wolcott, 1994). As a result, Wolcott (p.1) proposes whether the terms 'analysis' and 'interpretation' ought to be used interchangeably as these are ways used to go beyond the data and, 'using' the data to achieve meaningful comprehension, rather than plainly 'gathering' the data and re-iterating self-explanatory accounts.

Within the interviews and broadsheet diary entries, Steve was inherently articulate in providing descriptions but also critically dissected his own experiences through using his skills and knowledgebase as a developing expert patient and knowledgeable journalist. I felt that mainly using a description or narrative analysis purely throughout steps one to five would not yield sufficient or a further understanding in addition to Steve's own reporting, which was an already extensive and critical account of his experiences and the public healthcare system. An early interpretative and inductive approach was therefore useful in constructing an understanding of any meaning portrayed in the journey's events and experiences, where I was able to simultaneously refer to literature and theory for further conceptual analysis, confirmation and querying of my interpretations.

In addition, as the CS was exploratory in nature (Yin, 2009), I found very earlier on that I would not just be looking at Steve's experiences or the content shared in the journey, but also the ways in which he used certain language and reporting techniques to reach his audiences cerebrally and on an emotional level (intentionally or unintentionally). Therefore, this type of analysis required interpretation from an earlier stage (in line with TA phases), which would enable a deeper level of detail and exposure to the meaning of and behind his ways of sharing the type of health-related information and perceptions compared to the use of description.

Although Creswell (2014) proposes the interpretation of findings as the last step of the analysis, I integrated this step after the initial reading and familiarisation of the data. I was constantly aware of certain questions during interpretation such as, *what lessons and important points were demonstrated in and as a result of the interviews*? This was a critical outlook that I adopted very earlier on as a result of following Creswell's suggestions. However, I used this step earlier than suggested within the analysis, as Steve was a critical reporter himself and it was necessary for me as a researcher to ensure that I was able to interpret meaning and contribute a worthwhile understanding of an already extensive account of oesophageal cancer-related events. This strategy of analysis was influenced by the hermeneutical approach (4.5.5) which influenced my interpretivist lens when trying to understand the meaning from the data.

I found Creswell's (2014) sixth step useful but as mentioned, this was used earlier on within the analysis alongside confirmation and comparisons of my interpretations against the literature and theory. Although Creswell proposes interpretation as the last stage, it is argued that interpretation is an inherent and unavoidable process to qualitative analysis even when unintentional (Laverty, 2003), as no matter how objective or 'bracketed' (Husserl, 1931; McConnell-Henry, Chapman & Francis, 2009) from the data one tries to be, the researcher is human who can only make sense of something though interpretation (how they see and perceive things) (Herrmann, 2013). Likewise, if a description (as proposed in step four) is regarded as an objective account of the data, this may not be the case as rely upon our understanding and perception of the world to then be able to create a description of something in the first place (Vygotsky, 1997). Therefore, this notion, along with the phases of TA, reinforced my decision to explicitly acknowledge the existence of my interpretation from the beginning stages of analysis.

In addition, the sixth step was a useful and influential step guiding the conclusion of this thesis. In line with the step's recommendations, the implications of the findings and discussion were situated within the wider health, social and current media context. I was then able to discuss the usefulness of the information I presented as a result of my analysis and the importance of the overall research. Although Creswell puts forward a certain order of steps, I found the guidance of the steps to be flexible and used these at various stages to aid the practical qualitative processes. I also used the guidance of each step as a springboard to aid my thinking and inclusion of certain discussion points, such as considering the impactful lessons that the research had to offer.

4.5.3 Analytical Guidance from Case Study Methodology

Case study methodology allows for an inductive and analytical process in research (Yin, 2009). To guide the analysis of my case study data, a few CS analytical techniques were used as recommended by Yin (2013) to further support analysis of this in-depth case (Steve's reporting of his cancer journey). These

consist of five techniques. However due to the qualitative nature of this study, some techniques were not directly applicable such as 'cross-case synthesis' due to there only being one case, and 'pattern matching' as there were no clear patterns that could be observed as the journey (at the end-of-life) was unpredictable with Steve's health and treatment options available. I therefore chose to use the following two techniques from Yin's CS guidance.

The first approach was that of 'explanation building'**.** The aim of this technique is to build an explanation of phenomena within the research through a structured way as chosen by the researcher. This may be done through an iterative process where explanations are built upon or changed in accordance with the findings occurring from more data analysis and from multiple sources (also linked to triangulation, which can help to verify a potential explanation, see 4.6.1.1). This is demonstrated within the Findings and Discussion chapter (chapter 5), where I have provided explanations for Steve's preferred use of language when describing his perceptions of his cancer, which then changed overtime for the purposes of aiding audience understanding.

Secondly, I used a simple 'time-series' analysis. For this technique, events or phenomena relevant to the context are studied are traced over time. This technique may be more appropriately applied to experimental research where a variable can be observed as changing or measured (Yin, 2009). However, as Steve's BBC Radio 4 interviews were chronologically recorded, I viewed that it would be useful to take influence from this technique to trace any changes in emotions and influences associated with his health and treatment undertaking. One example of this was the intermittent qualitative analysis of when and where the 'acceptance' of the cancer diagnosis was sustained at various phases of the cancer journey. As such, the time series analysis also helped me to decide upon whether to pick a certain topic as a sub-theme or even a main theme due to its prominence occurring over certain times in the journey (diagnosis, referral, treatment), which had the potential to encapsulate noteworthy or significant details about the experiences in the journey.

4.5.4 Thematic Analysis

Thematic analysis (TA), is a method for identifying, analysing and reporting patterns in data which are then grouped as themes to show the main, or significant points of interest across the qualitative data sets (Braun & Clarke, 2006; Willig, 2013). Braun and Clarke (2006) argue that a lot of qualitative analysis is essentially thematic that has been claimed to be something else, such as interpretative phenomenological analysis (IPA) or discourse analysis, where the same techniques for analysis have been used but within a different context for different research intent. As such, the authors note that there has been a lack of standardised and clear guidance on TA in the past and therefore, six phases of analysis were outlined to address this issue to introduce rigour to the categorisation of phenomena, events, experiences and people studied in research. A recent article by Roberts, Dowell and Nie (2019)

has attempted to provide an example framework to help researchers using TA in the rigour and reliability of the method which was modeled by the development of a 'code book' for the purposes of standardisation.

As TA is independent of theory, it can be used as a tool for analysis and is therefore compatible with a theoretical framework that may be currently relevant or adopted later on in the research process (Braun & Clarke, 2014). One of the strengths of TA is that it is a flexible and adaptable method according to the type of qualitative research method. The method can be underpinned by a particular theoretical framework or epistemology (Braun & Clarke, 2006). Equally, it can act as an independent tool of analysis, separate to a theoretical or philosophical position. Therefore, TA, unattached to an underpinning, has its practical use in any field of research and is often implicitly regarded as a realist and technical method of categorisation of data (Roulston, 2001). As stated by Braun and Clarke, it is a foundational recipe which can be used to guide analysis in any qualitative context. This has been demonstrated by the different manifestations of the method that have adopted specific epistemologies, theory, or reasoning (inductive/deductive); such as grounded theory (Charmaz, 2006; Strauss & Corbin, 1990), discourse analysis (van Dijk, 1993), narrative analysis (Smith, 2000) or template analysis (King, 2012).

However, Nowell, Norris, White and Moules (2017) Nowell acknowledge that the flexibility of TA is something that could be manipulated when used by different paradigms, which can raise questions about the validity and reliability of the analysis conducted. With the different steps or approaches to analysing the data, by different subject areas (business, psychology, sociology), a lack of standardised analysis practice had meant that the paradigms may claim to carry out a true TA when in reality, differences in how data has been approached means that the essential elements that guide a trustworthy and replicable TA are missed (Nowell, Norris, White & Moules, 2017). This can indicate a mis-match of TA across the differing research disciplines (Guest, MacQueen & Namey, 2012). Therefore, the six phases discussed by Braun and Clarke (2006) provide a skeleton for analysis that can be adapted and added to (with theory or an epistemology) to suit the needs of the research context and question.

TA is emphasised as being useful for identifying, analysing and reporting patterns in the data which can facilitate a 'rich and detailed', yet complex understanding of the research question (Braun & Clarke, 2006). I believe that this type of analysis, complemented by the varying sources of data and the inductive approach used to build an explanation of Steve's journey with his cancer, was the most suitable method of analysis. As a result, I was able to draw upon similarities and differences across the data when developing themes, whilst using TA to act as a standardised analysis tool across all sources. As set out by Braun and Clarke (2006), I used the six phases to conduct and demonstrate my analysis

and with this, I used NVivo (https://www.qsrinternational.com/), a CAQDAS (Paulus, Lester & Dempster, 2014), on which I could produce colour coding of data, store and organise transcripts for easy retrieval of quotes. NVivo was also used to produce descriptive and observational links between transcripts and codes to help within the generation of themes. All phases are outlined below with a description of my method of working with the data in accordance with TA guidance, to create viable themes that could effectively portray Steve's cancer experiences and the way that these were reported for audiences.

Phase One: Familiarising oneself with the data

In this first phase, I began to make initial notes and reflections about the data during and after transcriptions of all interviews, and this process enabled me to become familiar with the data and Steve's journey. This phase is similar to the practical first step advised by Creswell (2014). Listening to and then typing up all of the radio and television interviews myself helped me to 'immerse' myself in the data even more so as each significantly-reported event that led up to major events (such as treatment success and set-backs) became re-enforced within my memory when transcribing and re-visiting numerous audio interviews to check the accuracy of transcription and maintain my knowledge of the journey. This process facilitated my initial note-making, which continued as I re-read the data sets, which helped me to enhance my understanding of the journey and improved my analytical approach with every re-visit of the data. Once I imported the prepared transcripts into NVivo, I made 'annotations' to the texts (appendix 2), which provided me with a helpful and cohesive track record of my initial analysis that I was later able to build upon during phase six when discussing quotes that supported the themes and sub-themes.

Phase one was critical in the analysis process as I had not collected the data myself and therefore did not have the opportunity to be part of the generation of data or make true field notes during the interviews as a researcher might do when interviewing a participant.

Phase Two: Generating initial codes

After familiarisation and initial noting of the data, I then produced codes which selected quotes were filed under (appendix 3). The aim was not to code all of the content in a transcript, but to focus on significant quotes that echoed the noteworthy timepoints within the journey that included difficult experiences with cancer in any area of Steve's life (mental, physical, professional), and views and perceptions as a journalist reporting upon his healthcare. After coding was completed, NVivo was able to provide a visual representation of codes using colour (appendix 4), which allowed me to visually compare the prominence of certain codes within a particular transcript (Bazeley & Jackson, 2013). All of the codes were data-driven with the exception of two ('expert patient' and 'masculinity'). Although these were inductively noted, these were influenced by existing theory surrounding these two medical

and social concepts. As such, data surrounding these two areas were approached with certain questions in mind, which I then used to code around.

The initial codes were latent and descriptive in nature that would then be developed during phase three when improving, combining and condensing codes to create a feasible theme that captured the essence of each stage of the journey and various significant events and experiences that were reported (captured under sub-themes). According to Braun and Clarke (2006), codes are often 'broader' than themes (units of analysis), and this is why reviewing themes after they have been created is an important phase to ensure themes are not generic or descriptive which is instead the purpose of coding (a process in helping the researcher in developing familiarity with the data).

Phase Three: Searching for themes

To aid the identification and development of themes, I used the explore function within NVivo which created an 'explore diagram' (appendix 5 & 6) to act as visual representations of the codes ('nodes') that were prevalent in the transcript. The number of codes present within an interview helped to demonstrate the amount of significant events, experiences and views shared within the space of the interview. As mentioned previously in phase two, only noteworthy data that echoed the important timepoints, incidents and viewpoints were coded. Other data extracts such as back-channeling between Steve and Eddie were made a note through annotations, which would prove to be useful in understanding the interactions between Steve and other case members within the interviews.

Once potentially meaningful nodes were 'explored' on NVivo, further manual analyses were conducted to determine the actual significance of the nodes depicted in the explore diagrams. It was important to conduct a manual analysis rather than rely upon the depiction by NVivo queries as the number of codes (nodes) present within a transcript does not always provide a good indication of a conceptually meaningful theme that can be developed (Braun and Clarke, 2006). As the nodes were to be condensed, combined or unincluded in theme development, further analysis enabled this by a coherent display of queried codes in each data set. These were then defined by means of grouping similar nodes together (descriptive themes) to form a foundation for sub-themes in the next phase (phase four) that would require reviewing.

Phase Four: Reviewing themes

After developing initial themes and then reviewing these, I found it necessary to move back and forth between this phase and phase three as I had conducted more coding and recoding due to my progressing awareness and analysis of the journey. This process was repeated until the themes provided an overall picture of the story that the data formed. In their proposed stages of analysis, Braun and Clarke (2006) do not provide a guidance step on when to stop the refinement of a theme

as this it is not possible to provide universal guidance on when themes have been fully developed. Hence the concept of 'phases of analysis' which require transitioning back and forth between coding, analysis and provisional themes, is a robust method of reaching data saturation and evaluation a proposed theme. It is advised however, that when further and more recent analysis after the development of all themes does not add anything more substantial, the process of reviewing themes can be completed.

In order to review the order of themes, I had to continually organise the themes until they reflected the order and context of the journey that I aimed to present as a result of the findings. Comparison diagrams (appendix 7) in NVivo, helped me to locate which interviews had nodes in common. After collapsing the nodes where required for more coherent themes, I was then able to use the identified interviews as significant time points to base the order of the analysis upon. This tool helped me to confirm the chronology of events and also acted as an accuracy-checking map of when and where certain aspects of the journey were reported, which was more trustworthy and reliable than my own recollection of what stages in the journey events were reported at. For example, at certain stages later on within the interviews, diagnosis or referral to hospital were discussed at different timepoints to when these events actually occurred (the beginning of the journey). Therefore, the comparison diagrams shaped and confirmed the order of sub-themes and their respective quotes which did not necessarily occur in the order of the cancer journey itself. After the reviewing and refinement process, I re-read these in the order determined to ensure that the themes provided a clear picture of the overall story of the data. When themes did not achieve this, I re-defined any descriptive themes so that significant timepoints or concepts were encapsulated by these.

Phase Five: Defining and naming themes

A final thematic map of my data was created by hand which consisted of the final refinements of the themes. Influence was taken from nodes that were created within NVivo (appendix 8) as this provided a representation of the types of aspects covered within the reporting of the journey. In this refinement process, the focus lay with ensuring that themes were not defined as being too broad, but broad enough to cover the multiple sub-themes which captured the various reported events. To ensure that themes did not overlap in contents and the conceptual meanings of the data, I identified what each theme demonstrated about the data and in relation to the research question. In addition, the naming, renaming and organising of themes provided a structure to the sub-themes and analysis. This was because some events analysed were unrelated to each other however, these still 'fitted' under the same conceptual or time-related theme. As a result, sub-themes were instrumental to presenting my analysis in a clear and organised fashion, which could be easily followed and understood by the reader.

Phase Six: Producing the report

This thesis is the TA report. I used the annotations made in NVivo throughout the first five phases as prompts or reminders to aid the write-up of the discussion. During the period of writing-up the finding and discussion, I once again moved back and forth between this phase and phase five, which continued an iterative process in refining themes one last to ensure that the titles reflected and related to the content of each sub-theme and that the significant quotes chosen also linked back to the broader conceptual theme to demonstrate and support its prevalence. Deletion of repetitive extracts were made in the editing process and a logical ordering of themes were chosen to mirror Steve's journey as accurately as possibly.

4.5.4.1 Inductive Phases

It is important to note that a 'phase' is a process and not just a 'step' within the analysis. Although Braun and Clarke provide an order of conducting TA, the researcher is encouraged to move 'back and forward' between the entire data set, coded extracts and written analysis that is in the process of being produced, to ensure detailed analysis at micro and macro levels to continually build and improve upon analysis. I found the flexibility of the phases useful as I was able to move back and forwards between my analysis, initial coding and formal coding to change and enhance my analysis and interpretation, as my understanding of Steve's journey improved over time due to gradually becoming more familiar with each aspect of the cancer journey and with Steve as a reporter.

For the purposes of my research, I used TA to structure, guide the order and approach of my analysis, along with the general procedures set out by Creswell (2014, p.251) and an interpretivist epistemology, supplemented by certain theory analysis to compare and contrast the interpretations that I had made about Steve's experiences and perceptions. As I utilised an inductive method of analysing the data, relevant theories (empowerment, the five stages of dying), did not dictate the direction of the analysis. Instead these acted as cross-checks and comparative material when deconstructing Steve's unique experiences and experiences that are typical in cancer diagnosis and treatment.

4.5.4.2 Creating Themes

Braun and Clarke (2006) define a theme as being a category, label or title that captures something important about the data which links back to the set research question. In addition, a level of patterning or frequent contextual occurrences should be attributed to a meaning that echoes purposeful explanation or description of the data (again, in relation to the research question). Ideally, there will be prevalence of selected meaningful concepts within a data item (an interview) and across the data sets (all interviews, diary entries). However, the authors acknowledge that frequent instances of a theme shown across the data does not mean that the theme in question is more important or has

something more meaningful to demonstrate that a theme with less occurrences. For example, if 50% of the data fits into a theme, this does not mean that the theme is significant in establishing a real depiction of the data, or even answering the research question. Therefore, the 'size' of a theme is irrelevant to supporting important finding highlighted by the researcher, as a 'small' theme could also strongly represent a noteworthy phenomenon occurring within data. Researcher judgment is vital to determine what a theme is in the context of the specific research. Guidance from Braun and Clarke is to maintain flexibility in analysis and not to necessarily depend upon the quantifiability of concepts, but to instead identify when there is 'keyness' to a theme that capture the research.

I followed this guidance and looked at the prevalence and occurrences of topics in each stage of Steve's journey (pre-diagnosis, diagnosis, referral, treatment, experimental treatment and end-of-life). After fully familiarising myself with the data and the context, I conducted a deeper level of analysis, where I deconstructed significant events further to understand whether these events or experiences told me more in relation to the research question. There were certain accounts that Steve shared in which it was clear that these warranted a sub-theme of their own. I then decided to group these under a theme that coherently marked the significant time points in the journey (diagnosis, referral, treatment), as my aim was to present the journey in an orderly manner but clearly show where in the journey changes in Steve's direction in care and treatment occurred and how this was coped with. Therefore, the titles given to each main theme represent these time-points and the sub-themes chosen, encapsulate the very specific personal and professional experiences and perceptions that were shared.

4.5.4.3 Language in Thematic Analysis

The language used to describe the results of data analysis, particularly in thematic analysis is a critical window to the analytic procedures used or not used by the researcher. Braun and Clarke (2006) highlight language such as themes 'emerging' or 'discovered' or 'uncovered' from the data demonstrates a passive approach to data analysis, denouncing the time, efforts and critical analysis of the researcher, which *denies* their active and important role of identifying patterns and creating significant themes to aid a reader's sense-making of the research topic (Braun & Clarke, 2006; Mantzoukas, 2004; Taylor & Ussher, 2001). Therefore, the use of passive language suggests the themes reside independently in the data and these would objectively 'emerge' from analysis by any investigator, with any research background (Ely, Vinz & Anzul, 1997). Consequently, this language ignores the fact that the production of themes depends upon the researcher's perception, judgement, training interpretation and understanding of the data. The use of language when writing when writing about the use of the TA method, is essential in maintaining clarity about the nature of my qualitative research. This consideration had directed me to reflect upon my influence and contribution to the

data analysis, and how my background as a psychology researcher shaped my focus when beginning to understand particular events and experiences reported in Steve's journey. Upon carrying out reading about my chosen method, I had developed an improved and explicit awareness of my role within the data analysis and reporting which transpired through to the grouping and matching of events that took place in the journey.

Although I used a coding software (NVivo), I also manually analysed transcripts by hand, to ensure that themes were conceived through a richer analysis by my interpretation of the data as my understanding and awareness of the context of Steve's journey, in line with my research propositions, provided a deeper and more inclusive analysis of this. In addition, I was able to conduct a time-series (Yin, 2009) manually which was possible after my digital analysis and comparison of NVivo codes. This helped me to inform me when deciding upon the final written order of presenting Steve's journey, where I chose to avoid the use of passive language as this would not be representative of the active role within the analysis and discussion of data.

4.5.5 Hermeneutical Considerations

There are various facets of Interpretivism that come into play during the analysis process, particularly within hermeneutics, which is the chosen epistemology for the study. Three major considerations were taken into account and addressed as a result of further reading and reflection upon this subsidiary of Interpretivism. These include: the 'hermeneutic circle', 'double hermeneutics' and lastly, 'bracketing', which I have chosen to integrate within my reflections, as both of these research awareness skills go hand-in-hand and are personal to the judgement and perceptions of the interpretivist researcher. All three considerations are included within this chapter as they have practical applications and were used or made note of during the active stage of analysis.

4.5.5.1 The Hermeneutic Circle

The hermeneutic circle is an instrumental process to hermeneutics, which makes interpreting of experience more grounded in the context of time, place and situation related to events (Gadamer, see Warnke, 1987). In the context of research, according to Eatough and Smith (2017), the hermeneutic circle prompts researchers to use and analyse their data in a 'dynamic, iterative and non-linear' way. In doing so, exploring and examining the 'whole' to understand its 'parts' and examining the 'parts' in light of the 'whole' provides a holistic and better understanding of interpreted events through the researcher analysing data from different stances. This enhances thinking by shifting perspective on what meaning from data might mean. This is particularly useful as one of the main criticisms of interpretation is that interpretation involves possibilities and not facts (Guignon, 2006, p.188). Therefore, addressing multiple possibilities in the analysis stage allows for more perspective upon suitable explanation of meanings extracted from shared experienced by a participant.

In addition, building an overall picture without just a single focus upon the micro or macro understanding of turn of events, allows for a well-rounded interpretation of events. This method of facilitating analysis proves once again, the usefulness of hermeneutics for this case study as it is presented as a journey (from diagnosis through to palliative care). The various events that took place in the different sections of the journey can be understood by examining the overall trajectory of Steve's journey, and the trajectory can be understood through the parts of the journey, and the significant par that each event played in determining his overall experience and outlook with OC.

4.5.5.2 Double Hermeneutic

The double hermeneutic is widely acknowledged in phenomenological analysis, particularly interpretative phenomenological analysis, also known as IPA (Smith, Flowers & Larkin, 2009), which employs hermeneutics but to a deeper level to uncover the 'essence' of phenomena; especially those experienced. Originally, it was not 'bound' to phenomenology within earlier philosophies about existence, but when re-introduced by Heidegger (1927) in the context of his area of interest, hermeneutics has been greatly associated with phenomenology (*hermeneutical phenomenology).* However, hermeneutical concepts such as the *double hermeneutic* or *bracketing* are equally applicable to the many forms of interpretivism as opposed to solely phenomenology (Herrmann, 2013). It is the notion of 'double' interpretation which has been argued to add another layer of interpretation to an already interpreted version of events by the individual. As simply put in the context of research by Smith and colleagues (2009, p.3): "The researcher is trying to make sense of the participant trying to make sense of what is happening to them." Therefore, although an interpretivist stance may argue that an interpretation is the closest way of accessing a person's reality, a 'double hermeneutic' from the researcher's analysis creates cumulative effect of many understandings that can mean the original meaning that was given to an experience is not fully accessible, and in some cases lost, depending on the researcher's extent or validity of interpretation.

Ricoeur (1974) addressed the layers of interpretation that can arise due to the process of meaning-making and engagement of deconstructing events to gain an understanding of these. Interpretation in this context is seen as "the work of thought which exists in deciphering the hidden meaning in the apparent meaning, in unfolding the levels of meaning implied in the literal meaning." (p.XIV). Of course, this does mean that the layers of interpretation and *deciphering* original meaning inherently creates a conflict of interpretations. However, interpretivism is one of the most natural ways that humans can make sense of novel or unfamiliar situations (Thompson, 1981).

Although an established epistemology, there are shortfalls in using this type of interpretive method, and one way of addressing the unavoidable shortfall, namely the double hermeneutic, is through the use of reflexivity. This is encouraged not only for the sake of transparency of the researcher thought

process but also to inform the reader of explicit or implicit (sub-conscious) influences that affect the interpretation and meaning-making process (Shaw, 2010; Smith et al., 2009). It is also necessary to acknowledge any meaning lost in the researcher's interpretation of events, particularly if the researcher cannot perform a final cross-check of their analysis with the individual, or participant to confirm the validity of interpretations, which is the case for this case study. For further study reflections regarding this matter, see 4.5.6.

4.5.5.3 Bracketing and Reflection

Another method which has been seen to be important within hermeneutics is 'bracketing'; a method used to "mitigate the potential deleterious effects of unacknowledged preconceptions related to the research and thereby increase the rigour of the project." (Tufford & Newman, 2012, p.2). The concept was first brought to light by Husserl in 1913 (see Fischer, 2009) who deemed that in order to successfully achieve viable interpretation of events, external influences such as an individual's (the researcher's) bias must be reduced as much as possible (*bracketed*) (Klein & Westcott, 1994; Osborne, 1994; Polkinghorne, 1983). The main way to bracket from the research process, such as data generation or analysis, would be to create reflections in order to become aware of one's biases or assumptions and then set these aside (Laverty, 2003). To become aware of these preconceived ideas would mean that the researcher could then engage with the studied experience without affecting the essence (phenomenology) or meaning (hermeneutics) of this (Polkinghorne, 1989).

However, later thinking by Heidegger (1927) echoed that the individual (researcher in this case) and experience are co-dependent, as without experience, there is no sense of the individual. And, likewise, experience does not exist without the individual. As a result, bracketing is not possible as a person cannot separate themselves from the 'understandings' and the 'historicality' of one's experience (Laverty, 2003). As such, it is important to be aware of researcher biases and potential influences not to 'bracket' them but to acknowledge these to understand judgement and person origins of conceptualisation of reported upon events.

Within case study research, this notion is mirrored by Stake (1995, p.86) who refers to *propositional generalizations* as an important written account of researcher decisions which were made to organise data analysis and findings to provide a summary of interpretation. In doing so, this can allow for readers to judge the case outlined and create awareness of reasons for certain interpretation, which can help to *add their own parts to the story*. Thus, allowing the reader's own *naturalistic generalisations* to understand the case. This method is particularly useful in this study as the interviews were listened to nationally on radio and television. Therefore, interested readers of this case would have their own perception, understanding and experiences of listening to and interpreting Steve's journey that he personally shared. One notion that I reflected upon is my reasoning for

organizing Steve's journey as an intertwined journey of personal and professional experiences with the healthcare and cancer, as opposed to portraying these as two distinguished journeys. In doing this, such propositional generalisations helped to provide input into the reader's natural generalisations when reading a presented case study (Creswell, 2014; Stake, 1995).

I was not involved in the production or generation of data, therefore under the definition of bracketing and practicality, I was 'bracketed' from this phase of the data (raw data) and I had no influence upon the content of the interviews; types of events chosen to be shared or the way that these were shared. Data was naturally generated through conversation without a research context or research goal and I did not influence the direction of the interviews with a semi-structured interview schedule, for example. Therefore, my reflections as a researcher were made upon the origins of the data, but deeper reflections were made upon the interpretation of the data itself as an inductive approach was used for analysis and in the understanding of meaning from data. As I could not avoid my influence and perception as a researcher, a full reflection is provided in this thesis to address this (4.5.6)

In my research, I acknowledge my influences as a researcher and avoid the active bracketing as per recommendation by Heidegger (1927). My reflexive accounts have the intended purpose of demonstrating transparency of my thought processes; provide insight into my perspective and background as a researcher and person and, to allow myself and readers to critically appraise my role in exploring the research propositions. I have also found that reflection acts as a track record and temporal markers for my thinking and actions on the research and how this may have changed over time with building upon thought with more reading, becoming more familiar the data and picking-up upon other significant points with more context. Therefore, referring back to written reflections can change or enhance method and analysis technique.

4.5.6 Reflexivity

Reflexivity has been defined and explained in many different ways within the different fields of research (psychology, sociology, anthropology). Differences have also been discussed in the use of the terms 'reflexivity' and 'reflective accounts'. Equally, these terms have also been used interchangeably depending upon the field of research and whether researchers are familiar enough with the processes and scope of reflections with each type process (Mauthner & Doucet, 2003; Tufford & Newman, 2010). I have addressed my self-noting process during data collation and analysis as *reflective accounts* or *reflections*. In order to produce my formal reflexivity for the purposes of making my introspection transparent for readers, I was able to refer back to these accounts to produce this.

Shaw (2010) proposes reflexivity as an essential hermeneutical procedure when looking at experiential qualitative data. Aspects such as researcher-biases, bracketing and any other concepts

that have potentially influenced the methods and therefore findings can be described or clarified for the benefit of the reader to understand how the researcher has arrived at their conclusions. Typically for qualitative researchers, they are engaged with the language, stories and first-hand experiences that people have, to share. The role of the researcher is to 'make sense' of these stories with meaning to provide new knowledge about human experience or perception, and the impact of this in the wider context, for example, society; with a view to facilitate change where needed (Shaw, 2010). This could be implemented through policy and practice, or as put by Shaw, "enhancing understanding at an individual or institutional level."

A more research-practical purpose of reflexivity is to aid evaluation of credibility (4.6.1) and to an extent, the dependability (4.6.2) of procedural methods through transparency, as well as addressing philosophical approaches to the data such as bracketing (Shenton, 2004). During the data gathering and analysis phases, I kept a digital diary of reflections with a note of dates and times of these accounts made. This acted as an audit trail for me as a researcher (Houghton, 2013) as I could observe the changes that occurred in my interpretation of Steve's journey, as I became more familiar with the data. The more I became familiar with the data and the more I read around theory and associated research, I found that my understanding of the data and the journey overall was in-depth and more informed. This was also the case when as I came across more and more journalists in recent news who were also reporting upon their own cancer experiences, from which I could identify similarities and differences between these and Steve's experiences and style of reporting.

When I reflect back on the data collation process, I felt that I did not have the same opportunities that a qualitative researcher carrying out traditional data collection would have, such as having the opportunity to ask more questions to a participant that could provide more insight into their cancer and coping, or being able to prompt for further clarification about an answer given. Therefore, I had to take more time to understand the cancer journey to ensure that I could interpret events as close to their occurrence as possible to avoid analysis that was misrepresentative of what Steve's reporting. This was a different way of working with the data as typically in the past, I have conducted interviews myself and within this process, I have gotten to build initial impression whilst the data was being generated and I have usually had the chance to clarify and check my understanding of what the participant said or meant when sharing their views. After carrying out interviews, I would also write-up my own reflections as analytical thoughts would be 'fresh' in my mind and I could refer back to these at a later date to identify any biases or thoughts that forgotten about as interviews progressed. I was unable to follow this typical procedure that I was used to however this different way of working with the data from an early stage, improved my ability to work retrospectively with data and still be

able to implement methodological considerations such as case boundaries and applying techniques to facilitate rigour in the research with the use of pre-existing data (4.6).

Transcribing the data was a significant process helping me to remember, interpret and analyse the data that I was unfamiliar with at this point of time in the research. This notion is supported by Braun and Clarke (2006) who state that transcription is a key phase within data analysis, particularly within interpretative methodology, where meanings are created by the researcher, demonstrating that it is a deeper process than 'mechanical acts of putting spoken sounds on paper.' I found transcribing to be a long but essential process that I carried out. In addition, listening to the interviews and having not carried these out myself with Steve made me feel like an audience member, where I personally felt emotionally affected by the unfortunate events explained about his treatment and ongoing health and affection for his family. I found that it was unavoidable yet necessary to allow myself to experience Steve's cancer journey from a perspective of the audience first, to then be able to understand the effect that his reporting had upon people.

However, after reading, re-reading, and continuously analysing all of the data, I was able to compartmentalise the emotional affect that the interviews had upon me and I could identify and focus on Steve's reporting techniques and ways of investigating his healthcare that he had critically done. In effect, the more exposure that I had to reading the events described, the more I could *bracket* myself from the emotional affect, allowing me to dissect the reporting of events in-depth and from an analytical perspective. This is something that Rolls and Relf (2006) propose is useful for 'protecting' researchers in emotionally-charged topics, allowing them to develop their capacity in comprehending the phenomena under investigation and promote neutrality in the data collection and avoid emotional influence upon analysis as much as possible (Tufford & Newman, 2010). Overall, I had benefitted from being an audience member and then disengaging from this to an extent, to then engaging with the data as an analyst. This combination of perspectives is what I felt enabled me to interpret meaning and impact from the events and experiences shared. Creswell and Miller (2000) note that acknowledging one's beliefs and potential biases, allows for space to address these early on in the process so that these can be 'suspended' as the study progresses. This type of 'modern-day' bracketing moves away from phenomenological and hermeneutical origins to improve researcher stance in interpretivism.

Revisiting the data multiple times, even after analysis was conducted, helped me to reflect upon the reliability of my own interpretations as I would note whether I interpreted an event or experience in the same way as previously done. As my understanding of the journey became better, I progressed with analysis and continued to revisit interviews, and compare the written findings to my current

understanding of the data. I found this process to be reflective of a more contemporary version of bracketing called 'hermeneutic revisiting' of the data (Fischer, 2009).

Bracketing

My personal stance about bracketing (4.5.5.3) mirrors thinking by Creswell and Miller (2000); I do not believe that it is possible to entirely *bracket* oneself from the research itself, or the participant's story due to the researcher having their own perceptions and judgements of data outside of the use of theory and inductive analysis. Traditional Husserlian bracketing, derived from hermeneutic philosophy, implies that the researcher can definitively segregate their beliefs, attitudes and biases from the research, thus avoiding any type of influence upon the data and analysis. Therefore, this implies that bracketing is an objective and reliable procedure with clear boundaries that can contribute to the rigour of the research. I am aware that my background in health psychology influenced my perception of the data such that at times, I found that I was focusing more on the coping strategies that Steve used or had been potentially using during the journey; when in fact, there were other more noteworthy and concrete aspects that were more prominent in the data. After carrying out peer-debriefing sessions with my supervisors, this was brought to my attention at which I then reflected upon after reading my analysis through again and editing this after casting the health psychology aspects to a side and focusing upon other important facets evidenced through Steve's reporting.

On the other hand, I would argue that my influence upon the data was *bracketed* from the data collation segment of the research, as I was not involved in the generation of the data. Therefore, I did not influence the content discussed in the interviews or diary entries that could potentially satisfy the aims of the CS research. This allowed for a truly inductive analysis without any researcher bias. However, I was unable to member-check my interpretations with Steve directly himself, therefore although bracketing from the data generation was advantageous to keep neutrality in the data itself, this was also a drawback for me when undertaking analysis. Being unable to member-check meant that the interpretation process took longer as I was unable to clarify some experiences that were discussed briefly but were significant aspects of the journey that I found were worth exploring to understand the journey and Steve's reporting further. Debriefing sessions acted as researcher inter-rater reliability exercises for data interpretation where I discussed my findings with my supervisors, and these were either confirmed or questioned.

4.6 Strengthening the Case Study: Rigour and Validation

Rigour, also referred to as *trustworthiness* is the amount of confidence in the data collected, interpretation and analysis of this data and methods used to demonstrate the quality and standard of

a study (Connelly, 2016; Cope, 2014). In order to establish and show the trustworthiness of a study, the researcher should employ procedures in order for a study to be considered accurately by readers (Amankwaa, 2016). There have been debates within the literature as to what constitutes 'trustworthiness' in qualitative research and how this ought to be defined and ensured through research protocols (Leung, 2015). Nonetheless, the concept has been agreed to be a necessity within research (Connelly, 2016) and the most referred to criteria of creating and ensuring rigour is by Lincoln and Guba (1985) and Guba and Lincoln (1994), which include four main components: credibility, dependability, confirmability and transferability. To establish rigour and demonstrate the validity of my case study research, I made use of provisions proposed by the authors where possible and these are expanded upon within each section of a criterion. Due to the nature of the study, not all procedures were used to the maximum of their scope, which is also addressed in the respective sections below. In these sections, I use the terms 'rigour' and 'trustworthiness' interchangeably as done by Connelly (2016).

4.6.1 Credibility

Credibility refers to the confidence and truth of the study itself and the findings, which has arguably been noted as being the most important criteria specified by Lincoln and Guba in 1985 (Connelly, 2016). Questions such as whether the study has been conducted in line with standard qualitative procedures or if not the case, whether adequate explanations have been provided to justify variations in practice would be a few examples of querying the credibility of research. Lincoln and Guba (1985) presented a number of provisions that can be embedded within their research to increase the credibility of the study. As outlined by Shenton (2004), there are numerous provisions that are useful in active research, where the researcher has collected or generated their own data for the study. For the purposes of this case study, I included the use of different forms of triangulation, peer-debriefing and reflexive accounts or commentaries.

4.6.1.1 Triangulation

Triangulation is done by using a combination of two or more data sources, methodological approaches, theoretical perspectives or investigators to facilitate and produce credible findings (Thurmond, 2001). Denzin (1970) proposed four different types of triangulation: data triangulation, investigator triangulation, theoretical triangulation and methodologic triangulation. I aimed to use all of these methods of triangulation where possible. In addition, Creswell (2014) proposed the use of multi-level analysis, which when I conducted (4.5.2), mirrored a form of general data-analysis triangulation which I discuss below.

Alongside explanations of each method of triangulation, I have also provided brief reflexive accounts of how I used each method with relevant examples where possible. Reflexivity is an instrumental

process of attaining rigour in methods and analysis (Shenton, 2004). I therefore used this technique to identify the uses of each triangulation method in order to maximise credibility and reflect upon how the research would benefit from these methods.

1. Data-source triangulation

This method incudes collecting and using multiple data or datasets from different sources. For the current study, I used data that originated from radio interviews, television interviews, written media (such as newspaper columns), social media posts and blog or website visitor comments. Using multiple sources helps to confirm whether findings are still consistent across different contexts within the same study, for example, audio media and written media. In effect, creating agreement of interpretations made by the researcher across the sources.

Another important reason for the use of this type of triangulation is that one type of data may not cover the whole picture or story of events (Guba & Lincoln, 1994). Therefore, drawing upon different sources can help to identify missed opportunities for more comprehensive analysis leading to an accurate reflection of significant events. I found that different sources of data covered differing timelines of Steve's journey, in which some were more extensive than others in the breadth of experiences and occurrences of events covered. The use of different sources educated me on the various events that occurred at different times of Steve's cancer journey. This also guided my decision on which sources of data to focus upon and use as the foundation of my analysis, and which data I could then use to support my interpretations and potential implications of the data analysed. An example of this was after analysing the way Steve shared his personal experiences, I was able to support this with public web comments and listener calls to the radio station by assessing how useful his reporting and advice was for those living with or supporting a family member with cancer. The marrying of different data from different sources helped me to achieve confirmation of my interpretations and about Steve's aims of reporting his journey and his journey overall.

2. Investigator triangulation

The main purpose of using multiple researchers or analysts to gather, observe, interview, code and analyse, data is to limit potential bias and incorrect judgement (Denzin, 1970). This method helps to strengthen internal validity. One way of doing this is by working towards inter-rater reliability where researchers analyse data separately and discuss findings to confirm, agree or disagree interpretation of the data (Armstrong, Gosling, Weinman & Marteau, 1997). This approach is particularly useful in the interpretative paradigm where multiple perspectives and conclusions can be reached about the same set of data (Thurmond, 2001). However, I would argue that reaching a consensus on what a particular quote from the data might indicate is not the same as interpreting the quote accurately with original and intended meaning. This is something that I acknowledge with the added fact that I

was unable to conduct member-checking (Shenton, 2004) with Steve himself to confirm the validity of my interpretations and conclusions.

Due to the independent nature of carrying out doctoral-level research and the independent nature of creating a thesis, my analysis was therefore independently carried out. However, supervision with my professors acted as peer-debriefing sessions (Connelly, 2016), at which I discussed each theme and section of analysis I found, with them. I gained feedback on whether my interpretations made sense and were feasible in analysing and explaining the way the journey was reported. Additionally, my supervisors were able to identify any biases that were influencing my analysis, such as my theoretical knowledge of health psychology, which is my academic background. In doing so, I was able to take this feedback on board and isolate these biases through active introspective and written reflections and present behavioral and perceptual analysis that was evidenced only through Steve's quotes. As a result, I would acknowledge my supervision throughout the PhD as vital peer de-briefing sessions with senior researchers as a form of investigator triangulation.

3. Theoretical triangulation

With this method, different theories are drawn upon to analyse and interpret that data through multiple theoretical lenses. This is useful as data can be analysed in line with existing researched theory which can then be compared to the unique context of the case study to further understand the applicability of the theory or further understand just how unique the case is. The use of theories may also generate and influence specific hypotheses that can be supported or refuted, depending on the finding and conclusions (Carter, 2014). Therefore, theoretical triangulation also has the function of critically dissecting an outdated or irrelevant theory or, advancing a theory further if findings indicate support of theory as well as assessing credibility of the findings itself. For positivist or purposeful research, theoretical triangulation can be used to test various theories through means of the same dataset (Boyd, 2000), which is useful in a purposive case study with an explanatory focus (Yin, 2009).

An example of how I utilised theory is when trying to understand any transitions in the stages of death that Steve might have experienced at which I drew upon the popular theory of the Five Stages of Dying (Kübler-Ross, 1969). Comparing Steve's perceptions of death and the stage of death acceptance showed differences in how the theory proposed the order of stages and how this differed in this specific case study, allowing me to contribute a different perspective to the theory.

4. Methodologic triangulation

Thurmond (2001) describes two types of methodologic triangulation that can be classified into 'across-method' triangulation and 'within-method' triangulation. Across-method triangulation can involve both qualitative and quantitative methods, also addressed as multimethod or mixed-method

collection of data. Thurmond also stresses that is it important to note that the triangulation refers to the collection of data and not philosophical stances employed by the researcher (Goodwin & Goodwin, 1984).

Through the use of multiple methods, biases that may arise from one method can be eliminated with a supplementary method. In addition, the flaws of one method can be counterbalanced by the strengths of another method also helping to facilitate stronger and valid analysis. Due to the nature of the research and the use of qualitative case study methodology, I did not use across-method triangulation.

Within-method triangulation is where at least two different data collection methods are used from the same design approach (Kimchi, Polivka & Stevenson, 1991; Thurmond, 2001). Within qualitative research, this can consist of the use of a photovoice method used by participants, followed by a face-to face interview with the researcher. The material developed through the use of photovoice can then be used to supplement data deriving from the interview during analysis as well as guide the discussion during the interview. Within this case study, I did not collect the data but instead collated existing data available from the multiple information-sharing outlets such as radio interviews and written diary entries, which were used to triangulate findings.

5. Data-analysis triangulation

Using different analysis techniques can help the researcher to uncover different concepts and angles from the data which may not be achievable with just one method of analysis (Goodwin & Goodwin, 1984). Morse (2009) stresses that analysis should occur separately with each chosen analytic method and then be 'synthesised' or presented appropriately. The researcher should then identify similarities and differences between analysis steps or techniques to then be able to conclude how these affect findings and are beneficial in generating results and meaning from the data (Carter et al., 2014). I used this form of triangulation by utilising practical qualitative guidance (Creswell, 2014, p.251) and prescriptive analytical phases (Braun and Clarke, 2006) to complement each other to ensure comprehensive organizational and analytical micro and macro-level data analysis. It was important that I aimed to ensure that the methods focused on the same research focus to facilitate valid exploration of the data in line with the research question and case boundaries.

4.6.2 Dependability

Dependability in the context of trustworthiness of a study comprises of two facets. The first being reliability of results, which should be addressed by the researcher with a research design that can be used as a 'proto-type model' (Shenton, 2004), that can be followed or copied in a similar research context for reliable study findings. The second facet is concerned with the replicability of the study which is in itself addressed in the process of producing reliable results. Shenton (2004) stresses that

an extensive methods section or chapter is vital with consideration given to all aspects of data collection, collation and analysis to help create a useful and clear guide for other researchers to repeat study designs in the same way, if not necessarily to attain the same findings. The comprehensive and in-depth coverage of methods can also allow readers and researchers to assess the research procedures followed to allow for transparency and an understanding of whether dependable practices were carried out. I have addressed this by providing detailed explanations of what and how methods were used.

4.6.3 Confirmability

This relates to how consistent findings are and whether these would be repeated when carrying out the research again. This is closely related to dependability and is a similar concept to objectivity in quantitative research (Shenton, 2004). Neutrality in arriving at results and eliminating investigator bias are important factors in allowing true replicability (Connelly, 2016). One way to address this is through peer-debriefing as discussed earlier under investigator triangulation (4.6.1.1).

Qualitative researchers should also provide audit trials of analysis with an explanation of how models of analysis were used to interpret data. Reflexivity accounts would be another way of facilitating confirmability (Shenton, 2004; Thurmond, 2001), but only to an extent. The perceptions and understandings of the researcher can be read to pinpoint any possible investigator bias that has been either address or left unaddressed, and this can be taken into consideration when replicating the study as to address potential issues and eliminate bias. I have provided a reflexivity account so that this very issue can be addressed through transparency and so that readers can understand my background influences and thought process that I have actively acknowledged in the analysis and write-up of the thesis.

4.6.4 Transferability

Shenton (2004) outlines that transferability looks at the extent to which the findings of one study are applicable to other situations in a real-world context. Stake (1995) and Denscombe (1998) suggest that even is a case may be unique, it is still an example within a broader group and therefore, the prospect of transferability should not be rejected. It is not possible for all of the findings from Steve's journey to be applicable to other journalist's stories but certain elements such as factual reporting (dealing with strong treatment and uncomfortable side-effects) and the impact upon audiences, will be 'transferrable' more generally.

Although the current case study findings may not be directly transferrable to other people's life experiences and health(care) journeys with cancer, the use of the case study methodology is clearly applicable to other journalists or public figures in the media who have been through, or are in the

process of sharing their health story. I discuss transferability of the case study and transferability of the implications of the findings within the concluding chapter of this thesis.

4.7 Presenting the Case Study Report: Structure

Yin (2014, p.187) suggests that the structure of a CS must be organised in a way that constitutes the CS report's compositional structure. There are six types of proposed structure and the use of each is dependent upon the purpose of the study: explanatory, descriptive and exploratory. Table 4 depicts the compositional structure that ought to be used for specific CS research purposes.

Table 4: CS Purpose and Corresponding Structure (Yin, 2014)

Types of compositional structure	**Purpose of case study**		
	Explanatory	**Descriptive**	**Exploratory**
1. Linear-Analytic	**X**	**X**	**X**
2. Comparative	**X**	**X**	**X**
3. Chronological	**X**	**X**	**X**
4. Theory-Building	**X**		**X**
5. Suspense	**X**		
6. Unsequenced		**X**	

1. Linear analysis

This consists of the typical scientific report layout which is organised by the order of IMRAD (introduction, methods, results, analysis and discussion/conclusion). This structure is useful for submitting the study for publication and advantageous to students and researchers wanting to present their thesis or work in a cohesive manner. It builds the picture of the research gradually and in a step-by-step process, eventually leading to the insights gained and impact that the study has had within the area of research. This traditional approach is well recognised and useful in guiding the reader of the item to be researched. This includes why researching this is beneficial, how it was researched, what was found and what this means, and what could be the next steps in research as a result. This structure also acts as a 'recipe' for other to follow should they wish to conduct similar research.

2. Comparative

The study explores the same concepts or issues from multiple points of view for the purpose of testing, building and comparing theory or paradigms. The same CS material will be analysed two or more times

and can be done so from a relativist approach. Depending on the researcher's selection and the purpose of the study, the case may also be presented multiple times using various descriptive models to cover the main concepts of the researched phenomenon.

3. Chronological

Evidence is presented in a temporal order and follows a beginning, middle and end structure. As case studies cover events that occur over time, the report gradually develops upon this with description and analysis. The structure mirrors that of a story. If events are expected to occur before or after another event, this acts as a prompt for the researcher to further identify or research the phenomenon, which could tell us something more about what is happening. Therefore, chronological structures are helpful for the purposes of explanatory case studies.

4. Theory-building

This structure consists of presenting a different part of the selected theory in a new section of the report. As a result, different theoretical aspects are explored in relation to the data. This type of organisation can provide a rich and detailed representation of the data using the various aspects of a theory, showcasing where gaps in theory lay, which can then be developed with further analysis of the detailed CS.

5. Suspense

This type of report can be engaging due to its inverted structure of the linear-analytic report. The significant outcomes of the study are presented in the initial chapter or sections of the report. Subsequent chapters would vary according to the nature and outcomes of the study. Usually developing explanations of the outcomes are delivered with alternative explanations for outcomes show in the opening segment of the report.

6. Unsequenced

This structure is most appropriate for descriptive case studies. There is no particular importance given to the order of sections as an order does not change the descriptive value of reporting.

This case study is presented in a linear-analytic structure for the practical purpose of a doctoral thesis The exploratory nature of the CS also mirrors the chosen structure as the study explored the journey of cancer experienced by a journalist was uncovered through a chosen methodology and analytic method as shown chapter three and the current chapter respectively (before findings were discussed). The aim was to therefore provide a clear structure of the order and processes chosen to uncover the journey. In doing so, each chapter of this linear-analytic CS thesis was equally important in developing the case and written report. However, the major chapter (findings and discussion) used a

chronological compositional structure, as it was presented in order to intentionally demonstrate the order of significant events that occurred and were shared in the journey.

4.8 Ethical Considerations

In order to know which ethical issues that needed to be addressed, I firstly had to consider the type of data that I wanted to use and the type of analysis that I would be carrying out. Doing this allowed me to identify the potential ethics of using the various data from the media (where Steve had shared his personal cancer experiences) and whether I would need to notify certain organisations or gain relevant consent to carry out the case study.

An initial consideration that I made was regarding the type of analysis I would be conducting due to the nature of the data (pre-existing data). Heaton (1998) describes secondary analysis as the use of existing data to find the answer to a new research question, which differs from an original research question or motive that was established at the time of collection. As a result, this type of research which uses existing data for other research purposes not only potentially creates issues with the validity of the research (Thorne, 1994; Sørensen, Sabroe & Olsen, 1996), but also poses fresh ethical considerations that should be addressed by the investigator to ensure ethical and considerate practice (Irwin, 2013). This tends to include re-consenting of the participant for their data to be used in a new research context (Robinson, 2001). However, in relation to my research, I conducted a primary analysis on existing data that was freely available on the internet and was not generated as a result of formal or academic research.

In addition, the research included the collation, as opposed to active collection of data through the internet (4.4.2.1). Although this case study did not need to consider issues with 'secondary analysis' with the use of pre-existing data, (gaining consent or re-consenting a participant), I still considered multiple ethical issues that were important for me to address within the research to ensure that I covered all bases before commencing research.

One ethical consideration is that I used Steve's direct quotes without seeking permission from him. This was not possible as he had passed away. However, it is arguable that because all of the data was and still is publicly available, as a researcher I am able to use all information for study purposes without gaining consent (Rodham & Gavin, 2006). This is also supported by The British Psychological Society (Ethics for Internet-Mediated Research, 2017). It is also important to acknowledge that Steve freely shared his experiences with the public through the various platforms of media and therefore, would have been aware that this information would be stored on the internet and referred to by audiences. This was also questioned by Eddie (Int. 9): *…this is public property now though isn't it?* To which Steve replied, *…well it is, but I was thinking about this and in a way, there's no downside as I reflect on it*.

This confirms that Steve was aware that his story was made very public and would continue to exist online.

Another consideration that posed an ethical question was confidentiality. However, again, I would argue that Steve chose to share his experiences and therefore by conducting and publishing the study, I would not be revealing any new information that was not already accessible or known by the public. Additionally, as all data is still available on the internet and has not been removed, I would argue that Steve's family continue to consent to the freely accessible data online, which has the potential to be used in further reporting in the media and research purposes, as well as continuing to help raise awareness of oesophageal cancer.

To supplement Steve's reporting and triangulate interpretations (4.6.1.1), it was important to collate public comments that were made about Steve, his openness about his cancer and the effect that this had upon audiences. Using comments from website users and phone calls from radio listeners, were therefore used. In relation to using this type of data for research, Robinson (2001) suggests that when using pre-existing data, the researcher should to make a common-sense judgment as to whether they should seek consent from authors of blog comments. Data that requires an internet user to sign into a webpage for access should be also be avoided as this would require consent from users to use their information (Rodham & Gavin, 2006). When collating freely available data from blogs or article comment sections that mentioned Steve's cancer journey, I was sure to take these recommendations into consideration and also remove any person-identifiable information to ensure anonymity. This included names and geographical locations as although these were publicly observable, these users did not explicitly consent to being included within a research case study.

Having applied for ethical assessment for the case study to De Montfort University Faculty Research Ethics Committee, Health and Life Sciences (FREC, HLS), it was confirmed via email that ethical approval was not required, and I was granted approval to commence data collation and analysis (appendix 9).

4.9 Chapter Summary

In this chapter, the various stages involved in carrying out the CS have been discussed in-depth, with focus upon case members, study setting, the type of data used, and the different sources searched and used to improve and enhance interpretation of events and experiences. The exact analysis techniques and models used to guide analysis was described with a step-by-step explanation of how these were implemented for comprehensive and multi-level critical analysis. There was also a reminder of the use of the interpretivist paradigm through discussion of hermeneutical considerations that I used and took into account to guide the interpretation process. Collation and storage of data

using CAQDAS were also discussed and reasons for analysing certain data were given help to the reader understand where case boundaries were implemented for relevant data analysis. Ensuring rigour within analysis was also a significant section within this chapter, with outlines of the different methods that were used to strengthen analysis, build validity of findings and create transparency to enable reader judgement. The self-reflexive accounts in this chapter described my background and thought processes, and influence that this had upon the method of analysis. Lastly, ethics was discussed with reference to using pre-existing data from diary entries and interviews of a publicly known individual, without their direct permission. The role of researcher judgement in internet-collated data was seen as vital in this type of research, demonstrating that various ethical factors must be considered even with freely available data through the internet. The next chapter presents the outcomes of analysis, which consists of a discussion of the main findings.

Chapter Five: Findings and Discussion

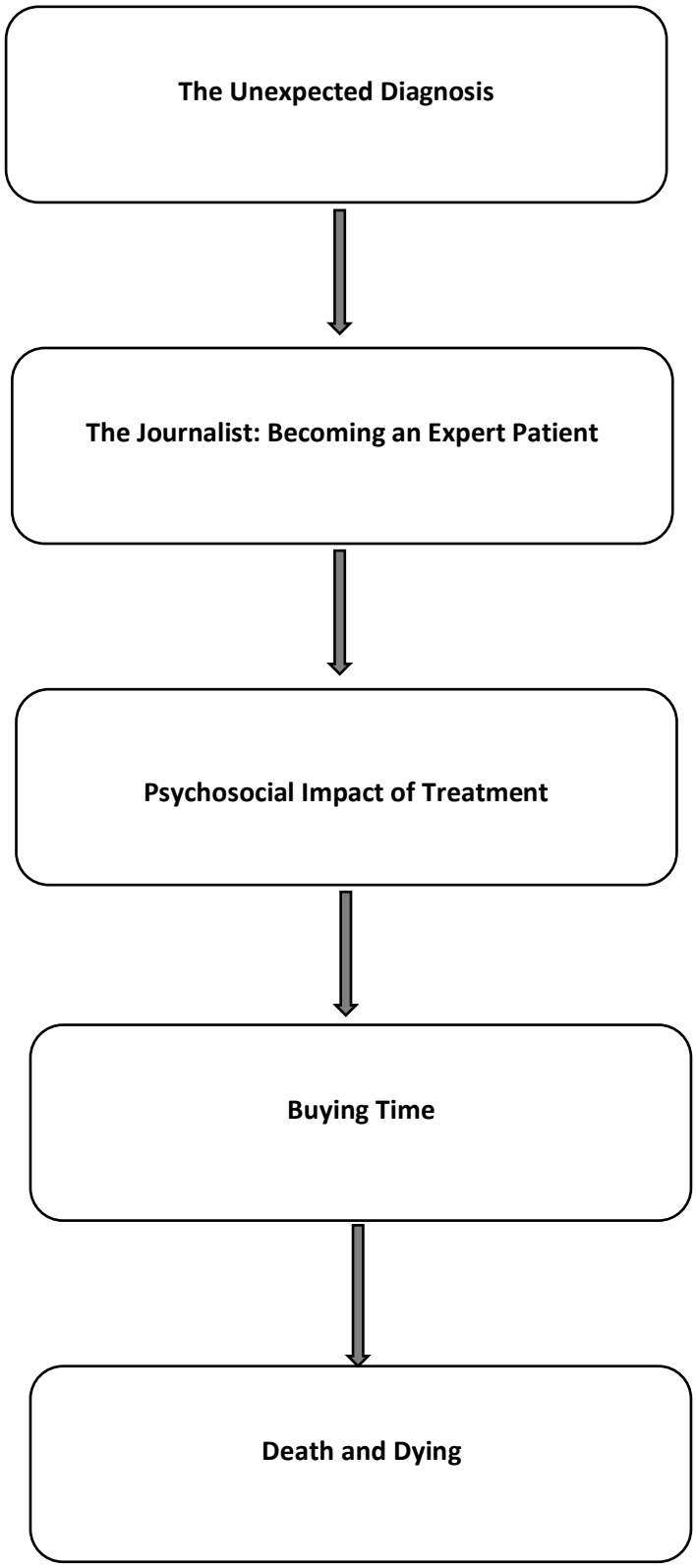
5.1 Introduction

In this chapter, the findings and discussion of Steve's 'story' are presented together as a journey, which entails the diagnosis, treatment and end-of-life experiences with metastasised OC. For clarity, a temporal approach has been used to show the significant time points in the journey (see figure 4 for the order of these events), with relevant sub-themes (table 5) that present important experiences, perceptions and events related to his health and the cancer. The ordering of themes reflects the chronology of the events that took place. See 5.1.1 for an overview of each main theme.

Threaded throughout this chapter are Steve's personal and professional viewpoints of healthcare experiences and factual processes in the NHS. In some cases, as similarly presented in the radio interviews, the layout of his experiences are accompanied by his own analysis as a journalist complemented by his personal thoughts and emotions as a patient with first-hand experience of cancer care which incorporated investigative journalism to facilitate knowledge-seeking on potential treatment options that could be pursued to extend his life. Therefore, within this chapter, techniques of engaging and educating his audiences in OC care, drugs and the wider consequences of health policy as a journalist are discussed with a further analysis of his experiences as an individual dealing with cancer. Hence, the findings incorporate a commentary on professional and personal aspects of the journey that were illustrated by Steve's sharing facts and evidence relating to OC interconnected with his personal accounts of adjusting to the physical and psychosocial effects of OC.

Journalism uncovered information such as drug and treatment policies and the best way to obtain specialist care and, to extend life where possible. This educated audiences and created public interest as these were activities that the average patient would not necessarily consider or have the opportunity of researching or critically questioning. For example, contacting a drug manufacturer directly or questioning the chief executive of the National Institute of Health and Care Excellence (NICE) on NHS decision-making and budgeting. This individual and professional reporting provided access to Steve's cancer journey through the story-telling of his experiences, which generated positive and supportive public and media replies: *It's provoked a huge response which is you know, one says enormously gratifying and I think it's telling us you know, not enough is said often enough about cancer…* (S: Int. 3). With the advancement of every interview, barriers to treatment and positive breakthrough events shared were supplemented by the various social, psychological and physical aspects of the health journey. These are reflected by the four chronological themes discussed in this chapter (figure 4).

Figure 4: Order of Themes: Timeline of Journey



5.1.1 Overview of Themes

Table 5: Breakdown of Corresponding Sub-themes

Theme/Journey Timeline	Sub-themes
The Unexpected Diagnosis	*My luck's run out* *I may have had some signs and symptoms* *It got quite emotional* Getting into The Marsden, a Centre of Excellence
The Journalist: Becoming and Expert Patient	A Reporter of His Own Body On the Phone to the Drug Manufacturers Looking Through *NICE Goggles*
Psychosocial Impact of Treatment	*Living in a Perspex box* *A victim of something* Holding on to Identity Cancer as an Independent Entity *I'm* [not] *at war with anything*
Buying Time	*A couple of lucky breaks* The Pressure of Time Hope with Clinical Trials
Death and Dying	*I could pop off at any time* *Living every day as if it's the last* *I certainly wasn't gonna give up* Fulfilling Wishes *A half-way house* A Lasting Impact

Themes one and two, 'The Unexpected Diagnosis' and 'The Journalist: Becoming and Expert Patient', encompass the beginning of the journey which started with the sharing of the pre-diagnosis and diagnosis stages. Steve's journalistic influence was present throughout these stages with various information-seeking and information-appraising related to the newly diagnosed illness. Therefore, the journey started with Steve guiding himself through the healthcare process using his critical skills and analysis, to become an extremely knowledgeable patient, which was further demonstrated with the succession of the next three themes ('Psychosocial Impact of Treatment'; 'Buying Time' and 'Death and Dying').

Themes three and four, 'Psychosocial Impact of Treatment' and 'Buying Time', introduce the more personal experiences of the journey, which included the impact of the cancer upon identity and adjustment to his changed life. The worry associated with the progression of the cancer was conceptualised and communicated through metaphor and personal narrative. The way in which these types of reporting techniques are used to represent Steve's perceptions and to facilitate audience understanding of cancer experience is discussed. The important concept of time and its inherent pressure to extend his own life with the hope of effective clinical trials is also discussed, along with various obstacles faced in the struggle of participating in treatment with a weakened immune system.

Lastly, theme five, 'Death and Dying' explores the response to the unfortunate news that further treatment was not possible. In his ongoing journalistic conversation with his friend and colleague Eddie Mair on the BBC Radio 4 PM programme, Steve discussed his thoughts about living with the limited time left before dying, discussing his plans and priorities before death. Considerations and organisation required for end-of-life preparations were explained, providing insight into Steve's preferences, which differed from the realistic possibility of dying at a hospital or hospice due to the eventual shut-down of his liver. A sentimental and intimate event (marriage to his long-time partner) was shared which, for one of the very first times showed audiences Steve's personal wishes as a person with a terminal prognosis.

5.2 The Unexpected Diagnosis

5.2.1 *My luck's run out*

At the initial 'two-week wait' diagnosis appointment at his local hospital, the consultant surgeon informed Steve that the OC had metastasised and lesions were present in the liver. However, Steve had already researched his symptoms online prior to the official diagnosis appointment when treated for anaemia by primary care:

> *What I really thought though was having gone to google, when I first got the suggestion when that you know anaemic and whatever, I just thought ok, I've got it probably, my luck's run out. I thought I'd had a fan- a charmed life in many ways. I've been a journalist, I've been all over the world, met some extraordinary people I've even interviewed Colonel Gadaffi* [laughs] *you know…* (S: Int. 1)

Steve suggested that being diagnosed with cancer was down to his luck, or fate. Before this, he had already become suspicious of having a malignancy and therefore to some extent, his gathering of information from various sources, including *friends of friends of whom were oncologists* (S: Int, 1), had prepared him for the news he would receive at the diagnostic appointment. This was shown in his acceptance reaction to the news and gratitude for his adventurous and fulfilling life, again which had been due to his 'luck'. Emmons and Crumpler (2000) define gratitude as an emotional state and type of attitude towards life which is a 'source of human strength'. Similarly, other research has found that gratitude, which relates to having a positive attitude and mindfulness state of mind, acts as an important factor in having resilience in illness experience (Algoe & Stanton, 2012). This may explain why Steve's reaction to his diagnosis, loss of life expectancy and loss of potential future life experiences was unemotional and neutral: *It didn't make me sad, it didn't make me depressed* (S: Int. 2).

In effect, Steve's perception of his cancer, being a product of 'running out luck', indicated his resilience throughout his journey, particularly when experiencing the multiple forms of cancer treatment (see theme 4, Buying Time: 5.5).

Steve continued to reiterate this notion of having a 'good life' in exchanges with television journalist Victoria Derbyshire about his initial thoughts of being diagnosed and how subsequently, this influenced his perception of his past life experiences and privileged opportunities:

> *I think quite early on I, for myself, I kind of worked it out and I just thought honestly well you know my luck's run out. I've had a pretty lucky life, I've done lots of things that a lot of people don't get a chance to do. I've been a journalist you know it's a, it's a, it's a keep you alive kind of job because you're always looking a new things, nothing I've ever looked at has turned out to be boring.* (S: Int. VD)

The concept of luck and cancer has mainly been discussed within the field of biomedical cancer research (Albini, Cavuto, Apolone & Noonan, 2015; Weinberg & Zaykin, 2015) , where it has been argued that maladaptive cell mutations which have no obvious cause such as smoking are explained be down to a matter of an individual's luck. This has been argued to be an inadequate yet common explanation of the variance in cell mutation (Rozhok, Wahl & DeGregori, 2015).

Looking at 'luck' from a psychological perspective is attributable to philosophical or spiritual associations in unfortunate circumstances such as having cancer (Hopman & Rijken, 2015). The concept of luck links to the way in which cancer is seen as uncontrollable, unpreventable and external to the individual's control. Acknowledging the presence and reality of the cancer, is one way which can lead to the acceptance of it. Kübler-Ross (1969) indicated that 'acceptance' is usually the last stage of dying and helps the person to un-attach themselves to prepare for death. In Steve's case, 'acceptance' was present very early on in his journey from the diagnosis stages, which is not in line with Kübler-Ross' initial guidance on the stages of dying.

In a later companion volume, Kübler-Ross (1974) addressed critiques of the theory that stages were seen to be prescriptive and it was assumed that individuals would pass through the stages in the exact order stated (Corr, 1993), with a main critique being that individual differences and abilities in coping were left unaddressed. Kübler-Ross then admitted that these stages were not chronological or prescriptive, nor was the aim of each stage to be attained by a patient. Instead, these stages provided mere guidance for the type of thoughts and behaviour displayed by a patient to indicate their stage of dying to health professionals and family. Within this accompanying volume, it was acknowledged that patients who accept their diagnosis early would mean that they have had enough time to come to terms with their 'fate'. Although this may be the case for some patients, this explanation is not

reflective of those individuals who have been diagnosed at the later stages of a disease and have not had much time to adjust to their diagnosis before progressing onto urgent treatment referral. Some studies have found that the individual's personality and their perception plays a major role in having early and high levels of acceptance and adjustment to cancer (Aarstad, Aarstad & Olofsson, 2008; Hopman & Rijken, 2015). The combination of taking the time to reflect upon his life and having wanting to live longer, better explains Steve's early acceptance of the cancer diagnosis.

Reaching or having acceptance, even at an early stage, does not mean that the individual has 'given-up' but instead, there is the realisation that the individual is not able to 'fight' anymore (Kübler-Ross, 1974, p.100). In Steve's case, the first part of this proposition was shown to be true, however, even at a stage four diagnosis, Steve had the energy to invest in life-prolonging treatment. This behaviour does not reflect Kübler-Ross' theory of greif and instead, demonstrates that acceptance may not only be about coming to terms but the added benefit of gaining perspective on one's current 'fate' and keeping a balanced outlook with options open for potential treatment and maintaining quality of life (QOL). This is something that is seen later on in the journey (theme 3: 'Psychosocial Impact of Treatment': 5.4 and theme 4, 'Buying Time': 5.5).

The change in previously living a fulfilling and good life to then dealing with the effects of cancer demonstrated the transition from living unconditionally and unrestricted to having a palliative prognosis. This comparison facilitated Steve's acceptance of his health and change in life situation. Looking back at positive life experiences acted as a coping strategy, helping to create a sense of fulfilment. Religioni, Czerw, Badowska-Kozakiewicz and Deptała (2019) suggest that positive life experiences may contribute to the acceptance of a life-changing disease. This has also been seen to create the potential for positive adaptation to new scenarios that arise as result of cancer (Andrykowski & Hunt, 1993), also seen as a form of post-traumatic growth (PTG), which facilitates adjustment to cancer through the use of simple mindfulness and appreciation for what one has or has had the chance to experience (Cordova, Cunningham, Carlson & Andrykowski, 2001).

In comparison, perceiving to have a less degree of control over one's health or the stressful situations that may arise because of cancer, can affect a person's QOL (Cunningham, Lockwood & Cunningham, 1991) and steer them towards adopting maladaptive coping and experiencing emotional distress (Dunkel-Schetter, Feinstein, Taylor & Falke, 1999). Steve's perceived control for his health, although external to him and beyond his control (due to running out of luck), did not lead him to feel emotionally distressed: *I didn't feel down honestly about any of it.* (S: Int. 1). This was the case as he was thankful and nostalgic of positive life experiences, that in effect helped him to perceive and then rationalise the presence of his cancer as having run out of luck (or good life experiences), which facilitated acceptance. This is resonant with the model of ineffectuance (Kastenbaum, 2000, p.231),

where lack of perceived control in one's life is a partial process of dying when dealing with the unpredictable nature of an illness and its trajectory; something that is beyond an individual's control, such as having cancer.

5.2.2 *I may have had some signs and symptoms*

Prior to the diagnosis, Steve had experienced physical symptoms that although were unusual for him, did not make him question enough to prompt him to seek advice from his general practitioner. Not seeking medical attention is a well-known sociological phenomenon within men's health due to being influenced by cultural stereotypes about masculinity and gender role socialisation (Connell, 2000; Lee & Owens, 2002) such that men feel the need to portray stoicism, self-reliance and independence which is seen to be compromised when seeking help (Smith, Braunack-Mayer & Wittert, 2006). In addition, for men who do seek help, they view their partners and friends as primary sources for advice and information as opposed to seeking professional healthcare. With initial symptoms experienced, it was evident that Steve was unacquainted with the possible gastric-related signs of cancer.

> *Go back a few months with hindsight, I can say I may have had some signs and symptoms- at the time, it really didn't feel like that. One thing that did happen I can tell you is that I would not eat very much- half a banana or half a sandwich, which for me is unusual (laughs). Nevertheless, and I'd feel sort of incredibly full but that was it really. And then every now and again, I'd eat something that would feel as if it was getting stuck, not in my throat but in the back of my chest.* (S: Int. 1)

Steve used imagery to describe the type of sensations that are experienced at the time of symptoms becoming progressively worse. In effect, teaching the audiences about the presence of significant symptoms that should be questioned when experienced.

> *Er the best thing- I can remember as a kid, drinking fizzy pop… and if you drink too much fizzy pop in too big a gulp, you feel it in the back of your chest er a lot of them (the audience) may remember this when they were drinking fizzy pop* (S: Int. 1)

As demonstrated by his experiences with OC symptoms, when experienced in isolation, they may not prompt enough suspicion in the individual to question the presence of a symptom such as discomfort from swallowing food or general pain sensations unless these become severe enough have an impact upon the individual (de Nooijer et al., 2001). Consequently, in keeping with these findings by de Nooijer and colleagues, Steve did not seek help until symptoms had become severe and unbearable. The exact event that triggered Steve to finally take action for these symptoms was recalled; when at lunch with his sons:

> *This happened with er Wagamamma's noodle meal, not Wagamamma's fault in the slightest I should say, er and so I got the- it sort of felt like I got blocked. I started salivating, I had to leave the restaurant and I was standing spitting… spitting and retching. It wasn't particularly painful, it was just uncomfortable, I didn't even have any trouble breathing.* (S: Int. 1)

These graphic explanations of the symptoms indicated just how advanced the tumour in the oesophagus had become. Rothwell, Feehan, Reid, Walsh and Hennessy (1997) echo that the severity of symptoms are not experienced until the cancer has significantly progressed in the gullet, blocking the way for food. And so, with symptoms not exacerbated until the tumour has spread to all layers of tissue, this does not always trigger suspicion of the more sinister indications for the symptom (Lewis, Marcu, Whitaker & Maguire, 2018). As a result, this can be a cause for delayed oesophageal cancer diagnosis. In Steve's case, this was a typical example of the stage at which symptoms become severe and acted upon.

One of his sons was already aware of this type of symptom (difficulty in swallowing) but in retrospect, had not seen the symptoms to be debilitating.

> *We'd go out for dinner and I'd see him maybe struggle to eat but I know it wouldn't be that serious. Whereas,* [son who lives away] *came home and saw quite a bad sort of attack as it were and it just sent him into a kind of like shock* (Son: Int. 4).

Seeing his struggle for the first time had a profound effect upon one of his sons that left him overwhelmed: *he just looked uncomfortable, looked extremely uncomfortable eating and that sort of sent me into a bit of a- freaked out a little bit*. (Son: Int. 4). Steve's previous episodes of chest discomfort were also seen by his sons as not being serious enough to warrant urgent medical attention which was also in line with Steve's own reaction to his earlier symptoms before the incident at the restaurant. Once again, this demonstrated that a lower intensity of symptoms can be vague and unsuspecting to the individual at the earlier stages of OC (Lewis et al., 2018).

The event at the restaurant led to Steve's sons ensuring that he sought help as soon as possible: *…in the end, the kids said right, that's it, doctors. I went to the doctor on the Monday…* (S: Int. 4). This is reflective of research that suggests that some men seek help after encouragement from family and friends (Denner, 2000). After having his blood tests sent off for testing, Steve was called on the same day by the out of hours health services (111) for concerns about anaemia. He then met with the consultant surgeon from his local hospital after an urgent GP referral.

> *You're so anaemic* [quoting consultant surgeon]*, you're going to need a blood transfusion so within about, within three or four days, I've gone from standing in the serpentine, listening to Tony Hall make a speech about something to do with*

> *the BBC, feeling pretty well and completely normal, or thought I did, to er sitting there and getting a blood transfusion and er the endoscopies followed, the diagnosis followed shortly after that.* (S: Int. 1)

The speed in which Steve was contacted about his unexpected anaemia after his blood test, to having a blood transfusion was rapid and Steve was extremely grateful for this; *to cut a long story short, the NHS were absolutely were astonishing.* Steve had not felt any symptoms of the anaemia, such as tiredness and the emergency doctor was surprised to learn that Steve had not been experiencing the any physical issues: *She said well do you have any difficulty breathing? ….are you having difficulty walking up the stairs? I said no, I'm fine… I'm feeling ok.* (S: Int. 1). Forbes, Warburton, Richards & Ramirez (2014) discuss that experiencing dramatic symptoms is more likely to prompt a person to seek medical help and this is the case particularly in men (O'Brien, Hunt & Hart, 2005). In Steve's case, anaemia-related symptoms were non-existent, except for unrelated chest discomfort. This demonstrated why help-seeking wasn't a behaviour carried out earlier on in the pre-diagnosis stages. This very issue encapsulates the difficulty associated with diagnosis of OC at early stages when the individual is otherwise healthy and not under surveillance programme for any Upper GI tract conditions such as Barrett's oesophagus (Allum et al., 2011).

According to NICE guidelines (2015), for the referral to endoscopy for suspected OC, patients must present with one or more symptoms. For example, there should be presence of dysphagia and or persistent reflux issues and or, with internal bleeding (for anaemia). As Steve did not experience any substantial issues indicating possible anaemia, this highlighted the difficulty for an individual to recognise physical indications of cancer, which is also echoed by (Jensen, Tørring, Olesen, Overgaard & Vedsted, 2014).

Steve had adopted a pragmatic way of understanding what was happening to him at the time of his preliminary diagnoses appointments through appraising his situation with a practical outlook. This was shown by the reactions displayed to the news he received about his life expectancy and lack of treatment possibilities. He was aware that he did not react in the way that healthcare professionals would have expected him to and attributed this to his journalistic lens. His reaction to his health status was not that of the average patient reaction such as feeling shock, extremely emotional and, or denial (Vos & de Haes, 2007).

> *…various meetings with doctors where I was being given bad news, I think they were slightly taken aback because I wasn't reacting the way that they had expected. That's partly because I think I knew and partly because I think I started to rationalise it or maybe I was just blocking or maybe I was just being a journalist about it and sort of you know looking at it from a kind of third-party position.* (S: Int. 4)

Here, the audience was given the indication that the reporting of cancer by Steve would also be practical and rational, with less influence of emotions. Steve was aware that he did not react in the way that someone with end stages of cancer would react. His investigative and journalistic frame supervened over any emotional frame that he may have had. In keeping with with his journalistic background, Steve rationalised his new situation using the facts available. Hence, he was able to view his situation from a third-party perspective and not react as doctors would typically expect. This behaviour reflected the 'acceptance' stage description by Kübler-Ross (1969, p.100), which is seen to be "almost a void of feelings" to effectively see one's end-of-life with a realistic lens and without the influence of emotions. It was clear that Steve had an accepting frame of mind even prior to his official diagnosis (*partly because I think I knew*), preparing him for the definitive news at earlier hospital appointments. As a result, the transition from having no diagnosis to being diagnosed, was less difficult to make, as previously information-seeking had also helped him to become aware of the possibility of a cancer diagnosis.

This provided time to partly adjust to the bad news before diagnosis, making post-diagnosis acceptance relatively easier; *when you put my very vague symptoms, next to serious anaemia, there's really only one thing that comes up first…. I just thought ok, I've got it probably…. at no point did I feel the diagnosis crushing me*. (S: Int. 1). Steve's reaction of acceptance is resonant with the processes of empowerment in which he was able to 'let go' of control surrounding his diagnosis, emotionally as well as perceptually, as he had very earlier on attributed this to running out of luck (5.2.1). Hence, this supported the acceptance notion that not everything is controllable in illness (Aujoulat, Luminet & Deccache, 2007). 'Letting go' has been seen to be an important step in relinquishing control altogether to help an individual to begin to search for meaning, for means of empowerment and potentially gaining back control (Aujoulat, Marcolongo, Bonadiman & Deccache, 2008). Finding meaning was a process that unfolded in Steve's journey through the use of his personal and professional journalistic research, which is discussed throughout the next four themes.

5.2.3 *It got quite emotional*

This sub-theme encompassed a number of events that prompted Steve's emotional openness to new and negative experiences as part of his cancer and treatment of cancer journey. Emotional openness is defined as the ability to share and communicate emotions with others and receive the same from others (Komiya, Good & Sherrod, 2000). In Steve's journey with cancer, emotional openness was an important and organic process that occurred during significant experiences such as the cancer diagnosis. Before discussing this openness, he demonstrated a rational and pragmatic outlook of his diagnosis and early adjustment to this due to high acceptance (Kübler-Ross, 1969; 1974). However, he

was more concerned about his family and their reaction to the news, which surpassed the intensity of his own emotions:

> *At no point did I think, I didn't feel down honestly about any of it, nor even particularly emotional…. The most difficult moment in the whole thing was telling my children who are very close to me that I had got cancer. The look in their eyes I will never forget… it's a blow, it's a set-back, but they've taken it in you know, pretty good spirits.* (S: Int. 3)

Steve's children came to terms with Steve's diagnosis which mirrored Steve's own acceptance. However, the fear and uncertainty that his children faced was emotionally touching to him as although he had a strong understanding of his diagnosis and the impact of this, he was simultaneously aware that he could have no real understanding of the impact that he had upon his family as a father, partner and a person.

> *You know what they meant to you, but you don't really know what you mean to them… they're slightly scared and that's the impression I got.* (S: Int. 1)

The worry that was seen from his children's reaction is demonstrative of a natural and expected response from family members (Kershaw et al., 2015). This is particularly the case when there is uncertainty of the trajectory of health and uncertainty of life expectancy (Edwards & Clarke, 2004). As Steve was diagnosed with stage four OC, this meant that life expectancy was greatly decreased. Hinton (1999) found that anxiety in relatives was more prevalent when death was 'probable' as opposed to 'certain', due to the uncertainty of a time-frame of when 'probable' death could occur. This can be linked to Steve's journey further down the line, when a certain early death was postponed with effective treatment (see theme 4: Buying Time). Kübler-Ross (1970, p.104) proposed that the patient themselves reach acceptance eventually and find peace at this stage of grief. However, it is often the family that requires help, support and understanding more than the patient. This notion was reflected in Steve's very early acceptance of his cancer diagnosis and future health-related plans which were easier for him to comprehend and adjust to, compared to his family: *So actually I think all of this has been easier for me to deal with actually than it is for anybody else*. (S: Int. 1).

Steve also compared his experience of dealing with the news of cancer to his family's experience and ability to cope with the diagnosis. While Steve did not feel *particularly emotional* (Int. 1), he acknowledged that it had been more difficult for his family to accept the change in Steve's health. Having received the shock of a cancer diagnosis, Steve was more empathetic towards other people close to him even when having to deal with the news than himself.

> *The only emotional bit and apologies if I don't quite get through this bit in fact, the really hard thing I found was telling the people that are close to you, my children especially. And what it was I think I, you know what they mean to you, but you don't really know what you mean to them. And it's the look in their eyes when you tell them, all the sort of- excuse me- a sort of slight, they're slightly scared and that's the impression I got. So actually, I think all of this has been easier for me to deal with actually than it is for anybody close to me.* (S: Int. 1)

He indicated that he was able to cope with distress and life-threatening news better than others which is typically the case for individuals with families (Kübler-Ross, 1696). But he also diminished the significance of his own diagnosis experience by comparing this to his family's experience, which he suggested as being arguably more difficult to deal with. Writer, Cory Taylor (2016, p.26) also used a method of dampening the severity of her own emotions and losses by arguing that another person's loss was more traumatic when compared to her own situation. For example, she downplayed her palliative diagnosis when she described a volunteer biographer losing her son which she argued to be a higher level of an emotional and traumatic experience than her own cancer diagnosis.

It is noteworthy to address that those with end-stage cancer such as Steve Hewlett and Cory Taylor would choose to dampen down the seriousness of their own situation through making use of situational and emotional comparisons to others' lives. One reason for this is due to higher levels of empathy felt. According to Jordan (1991), self-empathy is closely linked to empathy for others hence this may be why those with advanced cancer are compassionate and understanding towards others who may also be experiencing difficult and personal life events, either related or unrelated to cancer, adds to this notion that self-empathy, also be regarded as self-compassion, is a healthy attitude interconnected with being non-judgmental towards one's own feelings, thus being emotionally open to one's own situation and to others. Feeling empathy towards others at the end-of-life is also a positive mind-set which may aid a balanced perspective when experiencing difficult life events, which is an important element of mindfulness (Neff, 2003). Therefore, it is important to consider whether empathy towards others at this time in one's life could also act as a technique in coping with one's experience with distress in cancer, potentially facilitating mindfulness as well as emotional openness.

Steve's consideration for others demonstrated that he was a perceptive individual, with the awareness of the effects that the cancer had upon family members. As well as having empathy for others when nearing the end of one's life, the role of fatherhood and being a partner also produces compassion and strong duty of selflessness (O'Neill, McCaughan, Semple & Ryan, 2013). In effect, Steve was able to perceive the impact of the cancer external to his own thoughts and feelings that is, recognising the psychological impact of the cancer upon family and seeing this as a more important issue than his own coping with the diagnosis. As evidenced by (Helseth & Ulfsæt, 2003), a parent's cancer can create

insecurity as well as affecting the mental health and wellbeing of a child and other family members (Kershaw et al., 2015). When a parent recognises such emotion-related factors, this becomes the first step in making an illness situation 'secure' and maintaining 'normality' as much as possible for family (Helseth & Ulfsaet, 2005).

There was a shift in discussion about possible death which was not only about dying but the fact that Steve was worried about the implications of dying early, meaning that he would be unable to see his children grow and progress in their lives. Previously within the very first few interviews, specifically interview one, Steve's focus was centred on the prospect of an early death and the anxiety associated with this. This type of response to one's illness situation is referred to by LeShan (1989) as a dying person's superficial response to death. From interview nine and onwards, Steve became more transparent and open about his feelings and perceptions towards dying at a young age.

> S*: I feel I've had a pretty good run of it. I mean I don't want less, I want more.*
>
> E*: Yeah.*
>
> S*: I do want to see what happened with my kids. I do want to see you know the next stages in their lives, all the rest of it and it's quite upsetting when you stop to think about that. But am I weighed down by the thought? I don't think, I don't feel that I am.*
>
> (Int. 9)

Steve acknowledged that he was upset about the implications of dying early. However, he was clear in stating that he was not *weighed down* by the thought or possibility of missing out on such events. This suggested that Steve was psychologically able to overcome the set-back of missing out on seeing his family's future, which was indicated to be due to Steve's perseverance in his journey of cancer with various treatments. He was able to clearly identify emotional set-backs, and as such showed realistic self-awareness (Duval, & Wicklund, 1972).

One son described the contrast in Steve's willingness to express his feelings before and after the diagnosis of cancer. The description of Steve's change in emotional openness suggested that previously, Steve had a certain level of restrictive emotionality (Jansz, 2000; Levant, 2005).

> *I was gonna say on the changing that's physical obviously he can't particularly do that stuff. Well you can but not as much as you used to erm I think you've become more emotionally open in a way that I hadn't seen before. Erm (.) you've like you now talk about your feelings because they're sort of they're there to be spoken about and there's things going on whereas before that didn't happen. So there's more openness and some transparency with regards to emotions in that aspect.* (Son: Int. 4)

This type of response has been linked to the traditional masculine gender role and normative ideology for male behaviour (Mahalik, 1999; Wenger & Oliffe, 2014), which therefore dictates that men do not typically display emotions in order to portray psychological strength and stability and, to avoid being seen as vulnerable (Bennett, 2007). One reason for this lack of emotional openness or behaviour, as posited by Pasick, Gordon & Meth (1990), is the process of male interpersonal socialisation to conceal emotions such as fear, which contributes to inexpressiveness.

Steve's son continued to mention the change in emotional openness and described the most emotional expressiveness that he had experienced from his father thus far.

> Son*: Erm I was away on a ski trip in France erm so I found out through a phone call and I agree with Bertie, it was probably the hardest bit, the sort of, that initial shock of you don't know what, what's going on it's sort of it's all- you don't expect it to happen to you or like your dad erm…*
>
> E*: So when he rang you.*
>
> Son*: Yeah, I knew it wasn't good from the first sort of like the tone of voice and then it got it got quite emotional. It's the most emotional I've ever sort of seen him erm crying and I cried as well and it was very erm I I guess it needs to happen doesn't it. You need to sort of, you need to show your emotions like that but yeah it was difficult.* [Inhales] *Yeah.*
>
> (Int. 4)

Steve's experiences demonstrated that major life events such as a cancer diagnosis may inadvertently break down the barriers of ideological male behaviour norms such as unemotional expressiveness. As such, Steve's growth of emotional openness which stemmed from the diagnosis of cancer, had also impacted upon general areas of his life such that he was able to overcome emotional blockages that had previously prevented him from sharing deeper emotions with family. This experience in itself was representative of PTG (Tedeschi & Calhoun, 1995). Linley, Felus, Gillett, & Joseph (2011) found that the relationship between distress (due to adversity) and growth is mediated by emotional expression. Therefore, developments in Steve's emotional openness was instrumental to his own emotional growth which had potential to contribute to his overall psychological growth post-cancer diagnosis.

5.2.4 Getting into The Marsden, a Centre of Excellence

After receiving his diagnosis, Steve's immediate step was to pursue treatment within specialist care. Similarly, to the pre-diagnosis stages, he efficiently conducted his own personal research regarding potential treatment and care for OC. When researching the next steps in the cancer journey, Steve queried these steps with his personal contacts and friends who also provided him with 'insider'

knowledge and advice on how to pursue the best treatment possible. This information was also supplemented by internet and policy searches:

> *I'd done a bit of research already and I'd looked around and I'd spoken to people that I knew and friends of friends, some of whom are consultants in various forms of oncology and all the rest of it. And pretty much everyone said, if you can get there and the place- and you're somewhere near London, the place to get to if you can is the Marsden, the Royal Marsden because they have more clinical trials than elsewhere, they have specialist in lots of different cancers.* (S: Int. 2)

In gathering information on where he should undertake treatment, The Royal Marsden, a centre of excellence for cancer care in the UK, became a promising prospect for Steve due to its prestige and accessibility of world-leading research and clinical trials. Due to his inherent and inquisitive nature, Steve described how he was advised to pursue a referral to the Marsden in hopes of having access to experimental treatment and leading care to facilitate a longer life span. After his diagnosis appointment with the consultant surgeon at his local hospital, Steve was recommended to have a back-up plan should the referral to The Royal Marsden be unsuccessful.

> *So he said I suggest that what you do is pursue er a referral locally as well as to the Marsden so that you're kind of covering both bases, which is what I then set out to do…. There's a sense of time pressing, so I start to try and sort of wangle my way into the Marsden.* (S: Int. 2)

With initial delays having occurred with symptom display and recognition, and eventual diagnosis, Steve felt more aware of the passing of time without receiving any treatment. This is reinforced by the use of 'wangle', which suggested that he felt that there was a need to persuade the Upper Gastrointestinal team to accept his medical case and as a patient. Here was created an image of not entitlement, but privilege to be accepted for treatment at the Royal Marsden. This contrasted with the portrayal of treatment experience at his local hospital as discussed in section 5.3.2.

The impact of the hold-up in assessment and referral to The Royal Marsden was shown in Steve's emotional reaction: *It did reduce me to tears at one point and, I mean, I'm a journalist and so I sort of took about this task with sort of gusto.* (Int. 2). This reaction to a delayed assessment of his case contrasted with his stoic and practical nature as highlighted previously (5.2.2). The pressure of time and constant delays due to the holiday period and other unknown reasons, added to the combination of stress and hope associated with being accepting for treatment at The Marsden. At this point, very early on within the interviews, audiences were given insight into a 'quest' of a journalist who used his professional skills to aid his personal journey of cancer and healthcare.

The quest narrative (Frank, 1995, 1998) is a type of experience reporting seen here with Steve's efforts in trying to be accepted into the Marsden for his cancer care, where he was appreciative of the potential to receive word-class cancer care should he be able to overcome the hurdle of referral. A similar recollection of the quest narrative is seen later on in interviews when Steve was been to take part in experimental treatment but faced many challenges with the stability of his health and tumour growth (5.5). Frank stated that people with quest stories have a mission, or purpose in sharing these. One mission he states can be, 'to change the course of suffering for those who will come after.' This mission is arguably similar to one of the purposes of Steve's cancer journey sharing, which was to potentially help audiences learn of the early oesophageal cancer symptoms. As also seen later on in the interviews (5.6) another mission, or purpose of the quest narrative, was to make audiences aware of what dealing with the uncertainty of treatment consisted of but also the options available so that one may be prepared in how to gather information to be able to make an informed choice about the next steps in their cancer journey.

The task of contacting The Royal Marsden was further described:

> *I call the people at the local place and say, look, I'm getting a bit concerned that not a lot is happening…. And I said, look, I said to the specialist nurse, I said look, er you know if the consultant wants to tell me that this doesn't matter, I promise I'll stop bothering you. I'm getting a bit concerned about the passage of time because I'm thinking ey-up ten weeks and we've already got several weeks gone by.* (S: Int. 2)

Steve's actions to speed-up the process of his referrals at the local and specialist hospital draws parallels with the life span theory of Socioemotional Selectivity Theory (SST) (Lockenhoff & Carstensen, 2004). This theory proposes that the time remaining in an individual's life critically determines their priorities, influencing their selectivity in investing in meaningful activities or goals that are perused. In this context, due to Steve's limited time-frame before symptoms progressed even further, his prioritisation of extending his life was the primary goal. Therefore, his stated reasons lay with extending his limited life span in which he had a limited time-frame for when symptoms would become worse; *he* [local hospital consultant surgeon] *said well, in eight to ten weeks, you won't be able to eat, you'll need surgery probably to sort of begin to fix that and lots of other things will start happening to your liver and soon* (Int. 2).

King and Hinds (2012) suggest that individuals facing a foreshortened future may focus on their QOL or reaching personal goals such as travelling in a serious illness. However, at this point in time within the journey, Steve's priority lay with extending his life which would then allow him to spend more time with his family. Although SST is useful in explaining how remaining time in life can direct

important elements to focus on in one's life, it is important to note that prioritisation is also inter-linked to the carrying out activities and reaching goals (Lang & Carstensen, 2002). This being because prioritisation of events in one's life inherently creates meaning-making for the individual. This influence was shown in Steve's case, as he stated that it was important to him to pursue treatment so that this could lead him to his goal of spending more time with his sons and to see them progress in their respective lives. And so, the implication of a shortened lifespan not only guided Steve's course of action but also acted as a barrier in reaching important and meaningful goals that had to be overcome by prioritisation and using his professional skills as a journalist to navigate himself through the referral process. Thus, living longer by receiving care at one of the best cancer hospitals was the main focus immediately after the reporting of an unexpected diagnosis.

5.3 The Journalist: Becoming an Expert Patient

5.3.1 A Reporter of His Own Body

As the journey progressed, Steve was actively involved in his healthcare processes such as treatment decision-making. His actions were resonant with the role of the active patient (Ogden, 2012) and rapidly, he developed into an expert patient (Greenhalgh, 2009) with a vast amount of knowledge developed about oncology treatment, NHS-related policy and procedures. This knowledge helped to uncover the next steps of the journey and is something that came with healthcare experience, research and investigation, and continual self-reflection of the journey. Being an actively-involved patient possibly stemmed from the professional role as a journalist, arguably demonstrating that being an active patient within his cancer treatment was different to the average patient's experience of being more included in their care. Different skills and insights on how to find information from internal or external sources were utilised and at the same time, this modelled to listeners how this could all be done.

In conversation with Roger Bolton, Steve spoke about sharing the cancer journey publicly and his personal and professional reasons to learn from and become involved in the process and direction of the journey:

> R*: You've made yourself a reporter on your own body, haven't you?*
>
> S*: Yeah, but it's a, it's a sort of odd one because the thing is, I sort of approached the whole thing with a sort of slight journalistic head on, I think.*
>
> (Int. RB)

Later on, Steve had admitted, *I see my condition as a bit of a story* (Int. 9), which even though being an entirely personal experience, was conceived journalistically with an analytical outlook. He explored

and investigated treatment and specialist referrals which inherently required skills that are used within journalism. Therefore, the reporting of the *story* of his cancer was similar to what he already did for a living; working as a free-lance journalist and reporting on a range of topics which may not be in his field of expertise. As a result, his professional role was instrumental to the process of becoming an active patient, guiding him to seek information from various sources and self-educate in order to understand the possible direction of treatment. Active involvement is facilitated by the individual's relationship with their medical practitioner, however a patient's involvement can depend upon the seriousness of the illness and their personal characteristics (Thompson, 2007). This was evident within Steve's journey as he was keen to find out anything more related to cancer and its treatment. However, Steve's journalistic nature had already prepared him with the confidence and independence to find out information prior to appointments in order to be well-informed or even partly informed with knowledge to then be part of any decision-making. Steve's involvement from the very beginning was acknowledged to be something that the older patient, or the public in general would not necessarily be able to do:

> *But you know actually, navigating your way through the systems you know a bit of journalistic nous, which is terribly unfair I think. My mum here who's 86, well how would she do it? She wouldn't, it would have never occurred to many millions of people neither.* (S: Int. RB)

Similarly, this was echoed within a PM interview when describing the challenges faced to be accepted into the Royal Marsden: *Would she have been able to do that? Would she have been able to get on and off the phone? Would she have been able to sort of force the pace with things?* (Int. 2). This admission by Steve provided more reason for why he shared his personal experiences and methods of finding out information when diagnosed with a serious illness, so that audiences could benefit from learning ways of how to navigate themselves in their own health journeys, where possible. Furthermore, the guidance and knowledge provided through Steve's experiences educated audiences on how to identify the quality of care received and the importance of being involved in one's own cancer management and healthcare (further discussed below in the example of local hospital care). After facing multiple challenges in the beginning (delays in referral, not initially being prescribed standard treatment), he was aware and empathetic to the fact that discovering pathways for better care and gaining insider (expert) knowledge about treatment, was not something that the average member of the public would inductively or independently have discovered. This has seen to be the case with older people, the age group which is most commonly diagnosed with OC (Brown, Devesa & Chow 2008).

Media advocacy (Wallack, Dorfman, Jernigan & Themba-Nixon, 1993) was also present when Steve echoed the complexities faced in directing oneself through the cancer healthcare system to be of public

interest as it is probable that people may lack awareness to do this. Therefore, insight into important aspects of health and communication was focused upon and examples of how one could question and think critically about information provided by medical sources (healthcare teams, patient literature, policy) were usefully shown to model ways of active involvement. A prominent example of this which is discussed is when Steve uncovered the costs and dosages of self-funded treatment (5.3.2).

Steve was further questioned as to where his active involvement in his health originated from and whether this reasoning lay in needing material to report upon in the weekly PM shows. However, whether sharing his cancer story or not, Steve reinforced that he was prepared to actively investigate options and invest his time and effort into pursuing the referral to The Royal Marsden (even with delays), irrespective of the purpose of reporting back to an audience:

> *No, no I'm doing it, I'm doing it, I was doing it before. Before PM came on the scene or any of that. I was doing it with the health authorities. That's how I managed to get from* [local hospital] *to the Royal Marsden and how I managed to get the right course of treatment eventually prescribed in* [local hospital]*, which I ended up prescribing myself in the end, which is ridiculous.* (S: Int. RB)

Exploring and uncovering the cancer referral process, and getting the best treatment possible for him, also happened to usefully highlight the outcomes of being actively involved in one's own care. One outcome, which was eventually being prescribed standard treatment at his local hospital (something that the oncologist had originally thought Steve would not be able to handle the side-effects of). Zanchetta and Moura (2006), suggest that self-direction at the end-of-life (end stage cancer) can be influenced by personal factors such as open-mindedness and external factors such as a hospital's social environment. However, Steve's stated reasons to continue in the journey stemmed from the pursuit of treatment and extending his life but his professional background and resources as a journalist, allowed him to be able to move forward through each of the obstacles faced during referral and treatment. This was done through information-seeking behaviour from as many credible sources that he could explore (clinical experts, policy, medical literature). And so independently directing himself through healthcare in the beginning, related to personal reasons (extending his life) as opposed to purely having content to report back to PM audiences. This provided the true planned and unplanned methods that Steve used which was almost similar to his planning used for his shows in the media as a broadcaster or when he was editor of Panorama. Thus, allowing the audience to see Steve's development as an expert patient, using his professional skills, which also helped him to learn from the ground-up in, a very short amount of time.

To highlight his extensive and active participation in his treatment, Steve used the example of having not being initially prescribed the standard treatment for OC, a few times within the interviews. He had

been informed about standard chemotherapy by his expert medical contacts. And so, he prompted the registrar, using information-seeking techniques, then evaluated this information against his own research and prior knowledge to question the oncology team for further information and clarification. In doing so, Steve demonstrated ways of how questioning can be done if the individual is well-prepared with some background knowledge.

> *Now I know, because I had spoken to people that the standard treatment also includes a drug called Epirubicin. So I didn't want to sort of make an issue of it particularly. But I just sort of said, erm ok that's really good, thank you very much but I said, now I'm sure I read somewhere or something you know that there's a drug. It begins with e, is it epi-something?* (S: Int. 2)

After querying the standard treatment with the responsible oncologist, the registrar then informed Steve that they would instead be prescribing Epirubicin (the standard treatment) after all. This made Steve curious as to why he was not prescribed this in the first place, *I'm thinking hang on a minute, have I just prescribed myself? Maybe there's a reason why they didn't give it to me, so I say why wouldn't you want to give it to me?* (Int. 2). When querying this, he was mindful not to come across as challenging to the doctor which exemplified to listeners on how one could be involved in their own care without undermining or negatively affecting the patient-practitioner relationship. Earlier interventions in Medicine to increase patient involvement showed that asking direct questions to physicians can feel too threatening (see Greenfield, Kaplan & Ware, 1985). This can lead to adopting a passive role in one's own management of their health (Ogden, 2012). By sharing his technique used to subtly enquire about a doctor's decision-making, Steve provided to listeners, who may lack confidence or communication techniques, with how to question their doctor about something they were unsure of, or potentially disagreed with. In doing so, this promoted one of the initial ways of becoming involved in one's own health. Here, teaching and demonstrating communication and health-participatory behaviours to listeners, were seen as a function of the radio interviews.

The importance of questioning doctors for clarification was highlighted and this was shown to be easier when a patient came prepared with some background information or basic knowledge, which could help to shape the direction and type of treatment journey. The notion of being prepared was confirmed by the Macmillan nurse guest speaker on the PM show: *Write down the questions you know, Steve is a journalist and knows the facts and figures, but everyone, write don't the questions you want to ask and if you don't get an answer to them, ask what the answer is* (Int. 2). Steve was already carrying out such activities without being previously advised which once again demonstrated his skills as a journalist which fed into the management of his care and cancer. This began to facilitate his roles as a patient actively involved in his own care and influencing important decisions relating to this.

Steve compared his situation and abilities to that of the general public and so usefully questioned whether a person in his position would have been offered the standard treatment if they did not prompt the doctor at their local hospital to the same degree that had. He acknowledged that challenging a specialist doctor's decision may not be an easy task for an individual and this would require confidence to do so. He used the example of whether his mother would have been able to do this: …*would she have the nerve to say, even if she had known it was the case, I'm not sure this treatment is quite right you know* (Int. 2). This showed that for Steve to be actively involved in his own care, it was vital to have some knowledge about treatment but to also implement this knowledge for the benefit of his health, where appropriate. As such, the confidence to ask questions and prompt a doctor was indicated to be one of the first key factors to becoming an involved patient in one's cancer care. This was something that was shown numerous times particularly in the beginning of the journey with Steve having queried and prompted two hospitals for his referrals to specialist care. As discussed by Shaw, Adams & Bonnett (2004) and Ogden (2012), active patients make use of questions to influence their health outcomes which contrasts to those with a passive role. In addition to this, researching and querying treatments, role-modelled ways of doing this, which promoted the importance of adopting the active patient role to the public.

In the process of reporting on his treatment, Steve began to identify parallels between his experience of communication in healthcare and journalism, showing how he perceived similarities between the two disciplines:

> *Reminds me of journalese, you know in journalism, a really good story and an outstandingly good story usually means something terribly bad has happened [laughs]. Well, in cancer treatment, whenever they talk about progress, or progressive, watch out because it means the cancer is growing.* (S: Int. 5)

This indicated that his own experience of being diagnosed would be seen as an attention-worthy 'story' to report on. With the style of journalese seen to be dramatic and incorporative of hackneyed language (Thompson, 2010), Steve contrasted this with the use of meaning attached to language used in medicine. For example, the use of 'progression' which was explained not to be a positive development in cancer; the opposite of what Steve assumed to be the meaning of the word, even in the context of cancer treatment. His oncologist also emphasised that Steve thought this to be a positive thing in his cancer and had to explain that this was not the case.

> *I described a scan that he had had as showing progressive disease. Now Steve reflected on that and said well that sounds like a great thing you know, it's progressive it's a good thing. And actually, what we mean as oncologists when we say that, is that the cancer got worse…* (O: Int. 22)

Steve had therefore learnt the technical language and was able to conceptualise this to listeners. In the process of this, he highlighted to medics that the language used in health settings are often taken for granted and needs re-examining for the benefit of patient understanding. This did not only demonstrate his skills as a journalist but equally showed how much he had evolved as an expert and knowledgeable patient. The expert patient is an expert because of their knowledge about their condition, treatment and self-management where possible, but this is only a useful concept if the individual is involved in their illness (Greenhalgh, 2009). Furthermore, as echoed by Tattersall (2002) patients can only be fully involved in their illness if they understand what is happening in their current health. Equally, the language used in health consultations heavily contributes to this understanding, in turn determining a patient's involvement (Casarett et al., 2010). Steve's involvement in his health increased over time as he built his expertise about his illness, one way of which was through learning and understanding medical language. This had then transpired to helping to make key decisions about treatment such as taking part in experimental therapy (5.5.1 & 5.5.3). Learning the meaning of medical language added to the amalgamation of Steve being an informed journalist with first-hand experience and understanding of a medical issue (progression of cancer).

5.3.2 On the Phone to the Drug Manufacturers

After a discussion with his oncologist, it was suggested that if money was *no object*, the addition of Ramucirumab would be highly beneficial to his current chemotherapy regime which only included Paclitaxel. He received a quote for the price of the drug and private outpatient day care from the hospital but was unsatisfied with this:

> *S: … first quote comes back from the Marsden private patient's unit and it's £15,642 per four week cycle. Now that seemed like quite a lot to me so I thought ok. So I get on the phone to the drug manufacturers, Elli-Lilly and said-*
>
> *E: Wait wait wait wait wait so right, it's one thing to have all facts together and then you thought, I'll just phone them?*
>
> *S: Well, I thought why not? I'd seen a reference you see in some of the papers to the price of this drug…. They came back to me within well 12, 15 hours and said, ok here's the price. 2500 for 500 milligrams er £500 per er 100 milligrams cut a long story short… the total cost of which would be £9,600.*
>
> *E: Well, that's different from the 15,000.*
>
> (Int. 6)

The investigation into how chemotherapy was charged was another significant example of the journalism techniques that Steve used to his advantage as a self-funding patient. In the process of doing so, he had also educated himself upon the clinical aspects of treatment which was learning how

correct dosages were calculated for a person (based on weight and milligrams of the drug). This knowledge was obtained in the process of cross-checking drug prices with the manufacturer and this research even in the context of his personal illness treatment, once again intertwined with the professional role of a journalist and active patient behaviour. This created expert knowledge facilitated by both roles as Steve was able to draw upon his researching and reporting techniques from journalism, and physical, financial and social experience as a patient. This was so frequently done that both roles were fluid, inter-connected and complemented each other in the journey, so much so that there was no visible line as to when the patient role ended and when the journalist influence came into play. The process of uncovering the costs of private treatment to the audience, also highlighted the need to be critical when looking to self-fund for chemotherapy as mistakes in pricing could cost the patient thousands of pounds more. Exposing the pricing of private treatment and deconstructing how this was all done, provided insider knowledge to listeners on the type of challenges that they could unknowingly face in private treatment.

To aid audiences' understanding further, Steve looked into the clinical literature that showed Ramucirumab can extend a person's life by a couple of months, if effective. For listeners who would have also been deciding to undergo private treatment, Steve helped to make public the processes that the average patient would not necessarily be informed about as it is generally expected that correct and trust-worthy information is given by healthcare providers (Ridd, Shaw, Lewis & Salisbury, 2009). As such, passive patients rely upon medical professionals and representatives for information and usually do not question this as they believe it to be accurate (Ogden, 2012). In contrast, Steve's example of showing a mistake by a hospital once again highlighted the importance of being an active and involved patient, even in the pre-treatment phases as this ultimately benefits the individual (such as saving money).

The importance of active involvement in treatment is echoed by the work of Tariman, Berry, Cochrane, Doorenbos & Schepp (2012), who discuss that active patients tend to feel a sense of responsibility towards their own health and decision-making around this. Therefore, they do not assume all responsibility to their healthcare providers. On the other hand, it is important to acknowledge that the involvement demonstrated was a product of his journalism embedded within his active patient status. There was not only a sense of responsibility for his health but also an interest to explore, self-educate and break through bureaucratic barriers between the patient and the private and public healthcare system. Allowing the audience to be exposed to the practical side of having a serious illness, such as treatment costs, helped to advocate ways of developing active patient involvement through gaining basic clinical knowledge (how dosages are calculated), financial knowledge (methods of drug

costing) and lastly, the importance of being critical: having the confidence to question and find out information from sources when unsatisfied with the primary information received.

The difference in the original drug price given by The Royal Marsden and the second quote given after questioning this, echoed that a patient ought not to take certain information at face-value and that extra steps can be taken to satisfy the accuracy of this information. This is where, evaluation of information by comparing this to other sources, portrayed the amalgamation of journalist and active patient.

5.3.3 Looking *through NICE Goggles*

Half-way through the interview series, Eddie invited the Chief Executive of NICE on to the PM show, where the unavailability of effective drugs used to halt disease progression were discussed. Before this discussion, the writer AA Gill's recent article (The Sunday Times magazine: December, 2016) about a new form of treatment (immunotherapy) and the lack of NHS funding for this was used to contextualise the obstacles faced by patients with cancer who do not have access to expensive but pioneering treatment. Gill had been diagnosed with late-stage lung cancer. His conception of the treatment and unavailability of treatment acted as a transition to Steve's questioning about an effective drug, not currently funded by the NHS.

> [Eddie reading aloud article by AA Gill] *It's too expensive, £60,000 to £100,000 a year for a lung cancer patient, about four times the cost of chemo…. Thousands of patients could benefit. But old men who think they're going to die anyway aren't effective activists. They don't get the public or press pressure that young mother's cancer and kid's diseases get. As yet, immunotherapy isn't a cure, it's a stretch of more life, a considerable bit of life…. I just wonder and Steve will contribute to this, what you made of what he had to say about this.* (E: Int. 12)

Gill exposed the harsh reality of the lack of funding for certain cancer treatment (immunotherapy) and creatively raised awareness of this through his writing by appealing to audiences' sensitivities and emotions. This was a different approach to Steve who utilised his personal experiences as a patient and supplemented this with the use of NHS policies, clinical studies and expert opinion to raise awareness of treatment and the lack of funding for this. Gill's writing helped to act as a precursor to Steve's questioning to NICE about certain treatment availability in which he ironically, became an 'activist' for himself and for other people with OC, who could potentially benefit from Ramucirumab (the non-funded drug). Health activism (Laverack, 2013) is something that Gill addressed older men with end-stage cancer to lack in motivation. However, the practical and financial constraints of funding certain treatment were echoed by the chief executive of NICE:

> *Here is the other important component, which is actually what the NHS is being asked to pay. I agree that we need to be optimistic and default the interests of patients but ultimately, we have to strike that balance.* (C.E: Int. 12).

Using his expertise and oncology knowledge, Steve was able to find out how treatments were classed as eligible for public funding. This exposed the structures surrounding NICE decision-making, helping to highlight why certain treatment, which could help the public to live longer, has funding rejected. This was conceptualised using the metaphor of 'NICE goggles':

> *Now the problem is, that when looked at through NICE goggles, all the clinical trials have 50 percent or so of people who get no benefit at all and so the added you know, the added months of overall survivability or whatever, whichever measure you use, have a huge bunch of people in them who carry the figure zero into the calculation.* (S: Int. 12)

The use of 'NICE goggles' implied that the organisation viewed treatments in light of certain aspects which were only clinical and financial, but these considerations were seen as restrictive by Steve. The decision-making example given by Steve pointed out that finding of the study showed that 50 percent of people who do benefit from Ramucirumab have their lives extended by a significant couple of months to a year. However, the inclusion of participants for whom the drug had no effect, as per clinical trials, would significantly decrease the statistical effectiveness of the drug and consequently influencing NICE's decision to fund the drug. Although this is standard CTIMP (Clinical Trial of an Investigation Product) practice, Steve still chose to challenge the decision of not funding certain treatments that could help a person but only if they fell into the 50 percent of people who would end up benefitting from the drug. Schattner et al. (2017) state that it is important for journalists to take context and clinical practice processes into account when reporting scientific news, which in this case was not done. Later, Steve did acknowledge that he understood that balance and a regulation of resources was required due to the reality of financial constraints in funding every cancer treatment but did not further reiterate on his previous statements. He then went on to suggest a solution where patients could receive Ramucirumab for a chance to extend their lives and the NHS could still save money:

> *Now my oncologist thinks that if I start on Ramucirumab, she can tell within two cycles at about eight weeks, whether or not it's having any effect… why not let oncologists who think their patients might benefit from it, prescribe it? Why not insist on scans after one or two cycles and if there's no evidence it's not working, pull it again, so you're not exposing the NHS to kind of huge untapped or sort of unconstrained expenditure…* (S: Int. 12)

Even though this again would not be in line with NICE's decisions to fund a drug that is not statistically effective, Steve's efforts were reflective of media advocacy, where speaking about an issue to inform the public and question policy-makers is done using the media in an aim to advocate beneficial changes for society (Wallack, Dorfman, Jernigan & Themba-Nixon, 1993). In this context, Steve advocated for a potentially life extending therapy to be available to the public. In doing so, he utilised some of the strategies for promoting change as outlined by Laverack (2013): the first being, 'identifying the issue', secondly, 'analysing existing policy' for shortfalls and not addressing current public health needs, and lastly, undertaking 'consultation' either formally or informally to further understand the wider extent of the problem. Discussing the issue with his oncologist acted as informal consultation with an expert source in which a potentially patient-focused but money-saving solution was identified and proposed, backed by clinical expertise and analysis of clinical trial results.

Consequently, Steve had enhanced his role as a journalist reporting upon health in the media to advocating change by directly challenging a policy-maker. This was demonstrative of raising one's voice using policy to change systems and conditions (Dorfman & Krasnow, 2014a), proposing a change and providing a solution for ways to make decisions which were fair for patients. It is important to note that this solution was usefully suggested as a result of Steve's direct conversations with his oncologist, his experience as a patient and his ability to portray this on a media platform as a journalist. Media advocacy was made possible from an informed expert patient perspective with first-hand experience, supplemented by critical thinking and investigation that stemmed from his profession. In addition, Steve's contextualisation of the problem with the public availability of Ramucirumab was done effectively using Health Interest Framing (providing personal reasons for the need for the drug and his proposed treatment protocol if he were to have it). Using his cancer as a strong example for the importance of the drug and the need for It to be freely-available, provided an engaging way to report on a public health policy. As well as contextualising the issue, Steve presented the information complemented by a personal story to allow audiences to understand a health issue from multiple perspectives, to further educate them on the various factors that can be taken into consideration when advocating for treatment. It is necessary to note that although the use of HIF was engaging and helpful to facilitate the media advocacy, the reporting itself was not entirely accurate due to the dismissal of CTIMP procedures which require non-significant results to be included for overall findings.

5.4 Psychosocial Impact of Treatment

5.4.1 *Living in a Perspex box*

Steve stated that he was influenced by patient consensus and clinician warning that chemotherapy was a physically and mentally debilitating and stressful treatment intervention. However, he was fortunate enough to not experience the extreme physical effects of this type of treatment but did

describe the change in how he viewed his existence through the use of the metaphor, which was not being able to see or perceive things properly.

> *Before I started the chemotherapy, I was quite frightened. I was really worried about what was gonna happen and that does begin to induce its own consequences. Nevertheless, I was very lucky that the only significant side-effect is the Palmar-Plantar thing and also, moments of living in this like, I feel as if I'm in a Perspex box. I feel like I'm living in a Perspex bubble where it's all a bit scratched and you can't quite see out.* (S: Int. 1)

As discussed by Rabin, Ward, Leventhal and Schmitz (2001), there is a preconceived negative association with chemotherapy due to the uncomfortable side-effects which can be experienced in a multitude of ways such as affecting a person's physical QOL: sore throat, sore mouth, skin irritation, hair loss. As well as the physical effects of treatment, the mental, social and emotional functioning of the individual can be affected in their day-to-day lives (Hanks, Cherny, Christakis, Fallon, Kaasa & Portenoy, 2011). For Steve, the effects of having chemotherapy were psychosocial as well as physical as the notion of *can't quite see out* declared a feeling of being shut-in or consumed by bodily experiences and having to adjust to the effects of the cancer. Hence, making it difficult to focus clearly on the other things in his life other than the experience and recovery of his treatment and its side-effects.

One of the experienced side-effects, Palmar-Plantar Erythrodysesthesia, a toxic reaction to chemotherapy affecting the hands and feet causing redness, swelling and blisters (Farr & Safwat, 2011), showed one of the very first times where Steve began to address a shift in his usual clarity of his perception of the world. His perception and experiences were clouded, where his sense of vision and control of being able to live with clarity was no longer the same as before treatment.

The phrase *Perspex bubble* was also used interchangeably by Steve which implied that he felt a sense of separation to the outside world as his focus and energy was invested in his health and buying more time to extend his life to live to live as long as possible. Therefore, such a difference in health status and his stated reasons for wanting to live longer and making the active efforts to live longer, created a psychological separation from the world in the form of this clouded *Perspex bubble*. Here, Steve experienced the impact of the treatment on his body and mind and, having to adjust to a new way of perceiving things and maintaining his health. At the time, this impact had negatively affected his freedom in living his life without social restrictions due to being bound to the medicalised outlook of keeping his body 'safe' and infection-free (Illich, 1995).

As such, the metaphor was closely linked with Steve's experience of being restricted in his daily life due to the possibility of catching an infection, hence the feeling of living in a *Perspex* box. At the time

of interview ten, his oncologist had warned him of the dangers of being in public and meeting people socially, as this made him more susceptible to infection due to his weakened immune system. This was echoed when Steve was invited to attend a tribute event for his career, where there would be a number of people present.

> *You're you're very weak. You're extremely susceptible to infection… anyway we discuss discuss discuss. She* [oncologist] *said alright look, I know you wanna do it, I'm not gonna tell you, you can't but there are some rules. Go nowhere near public transport, you must go there and back in a cab…. Secondly if anybody has a cough or cold, please tell them to stay as far away as possible er and thirdly, not only should you phone us if you got a temperature, if you start feeling a bit off, call the emergency number.* (S: Int. 10)

The process of constantly having to 'protect' his immune system ultimately impacted his ability to feel, perceive and absorb his normal life experiences due to not being able to see things clearly, easily or safely as he could before treatment. Therefore, the lack of clarity in what he saw and perceived during treatment, was that of a feeling of being in a *scratched Perspex box,* where although things were clear, they were not clear enough due to new bodily experiences such as treatment side-effects that interrupted his normal way of living. There was also the case of having to adjust to the unfamiliar way of prioritising his health over other life aspects which wasn't the case prior to diagnosis, *I'd been refereeing two rugby matches a week, so I was reasonably fit* (S: Int. 1). The mental representation of feeling separated and trapped from the world, made Steve more aware of his surroundings now that he felt this separation. This left him with an awareness of taken-for-granted aspects of his life. These were now evident and impacted his ability to view and experience things as he once did: *I wonder if this is the last time I'll do this? I wonder if this is the last time, that I'll see this bit of Cornish coastline?* (S: Int. 2). This type of thinking or realisation of experiencing something for the last time in one's lifetime has been proposed by Kastenbaum (2000, p.253) as 'closing the book', where there are no 'new chapters' (experiences) that the individual will be able to live through and enjoy. This is seen as a continuous coping strategy that supports the acceptance of one's health situation. However, the way in which 'closing the book' is perceived (negative or positive) is depended upon the individual's satisfaction with their life experiences. In this case, Steve had felt that he encountered much opportunity in his life and therefore, although curious about the time left before his death, he was accepting of the fact of a cancer diagnosis (5.2.1). This reflects a positive and accepting 'closing of the book'.

Although Steve felt a separation from the outside world when feeling to be in a scratched *bubble*, he made an active effort to avoid being seen as different by others through maintaining his identity

through his physical attributes. The effort made of maintaining body image to deflect a cancer-related identity as perceived by others, is further discussed in the next theme (5.4.2).

5.4.2 *A victim of something*

Steve adopted a number of strategies so as to not appear like a cancer patient. For example, he avoided adopting a 'victim' identity as he did not want to be seen in this way by others. The loss of hair became an external and physical indicator of the cancer and, this was something that he felt he could control through hair-loss prevention treatment, so that others would not view him differently; as sick.

> *One of the drugs you get given called Epirubicin, it's a so called red, a red drug or it has the effect of er it attacks fast growing cells. So what the cold cap does is it essentially freezes your head* [laughs], *for a period, reducing blood flow to the follicles and therefore rather than elsewhere…. I sort of thought well I'd rather keep my own if I can, I think I'll feel better about myself maybe and people wouldn't look at me and think, oh there's a victim of something or other.* (S: Int. 1)

Steve did not only maintain his hair for personal reasons such as maintaining his self-confidence, this was also done to prevent being seen as vulnerable or a victim of cancer, particularly because he did not see the cancer as an enemy or a battle in the first place (5.4.5). Not wanting to be seen in this way by others was found in research by Hilton, Hunt, Emslie, Salinas & Ziebland (2008), who showed that people with cancer did not want to be seen as vulnerable or showcase visibility as a 'cancer patient'. Radley (1994) suggests that looking at a person's physical identity or traits are observations used to differentiate whether someone is 'healthy' or 'ill' even if this may not be reflective of the reality of the individual's health. Steve was aware of being socially perceived as a victim due to his newer physical traits which is why he sought to prevent this by undergoing cold cap treatment.

If he had lost his hair, being seen as a *victim of something* would create a social separation to healthy others in society. In turn, affecting how he felt; *I think I'll feel better about myself*. The notion of being seen to be a victim would socially portray Steve as helpless from being consumed by the effects of cancer treatment and would therefore be subjected to sympathy as a result, which is not what he wanted. This is something that the Macmillan Nurse guest also agreed was the consensus with others in the same situation, *it's a kind of sign saying there's something going on here and most people who haven't got any insight will say what's going on there?* (Int. 1).

Steve avoided sympathy by addressing the physical effects of the cancer treatment in a way that ensured that his identity remained a normal, independent and strong individual. This characteristic of being strong-willed was confirmed by Eddie; *Steve is absolutely stoic* (Int. 4), which enforced that Steve may not have been prepared to allow his social image and sense of strength to be compromised or

consumed by the effects the cancer. This notion is also echoed by Wenger and Oliffe (2014) who point out that stoicism is a masculine trait exhibited even during cancer management.

The use of descriptors used here (*victim* and *stoic*) and Steve's account of avoiding the classic 'cancer patient' image invites comparison with the literary notion of intertextuality. Discussions of common cancer speech and ways of referring to a person with cancer can often be intertextual with existing speech. As meaning from text or speech is not seen as being original or 'self-born' (Orr, 2010, see also Kristeva 1966-1968), instead meaning or ideas are borrowed for the use of other texts and can be modified or developed for the purpose of the context in question. In addition, this meaning can be conceptualised as being woven from one text to another to make a concept more contemporary or relevant to events happening in present day life. At other times, texts may implicitly make simple reference to past texts, to draw upon existing and continuing dialogue so that an author can demonstrate a point. This method of intertextuality was used by Steve when referencing battle metaphor p.165) and the 'victim' label, which is often synonymous or correlated with having or coping with cancer (Park, Zlateva & Blank, 2009). These concepts discussed by Steve were all existing phrases, well known and well-used socially (Sontag, 1978). However, in his discussions, this use intertextual relations between normative cancer speech and his own first-hand experience, helped to illustrate to his audiences just how contrasting an individual's actual experience in reality can be, compared to the picture painted by existing cancer dialogue, which is assumed to be the overall experience of the 'cancer patient' (Sontag 1978).

In addition, there is indication that Steve was aware that audiences themselves would be aware of the notions of being 'brave' and 'fighting' and 'losing' to cancer. The awareness of this taken-for-granted language was evidenced though Steve's use of statements**,** *I don't want to be seen as a victim.… I don't feel remotely brave* (discussed further on p.164). Referral to these words such as 'brave', 'hero' and 'victim', were used without prior explanation to his experience of being labelled as these but were used intertextuality to the set the scene to show how those with cancer are automatically addressed in these ways as 'a person with cancer'. This occurs because of an existing social dialogue about those with cancer being inherently seen as 'strong' or 'fighting a battle' immediately after receiving a diagnosis (Hauser, Nesse & Schwarz, 2017). Steve drew upon these concepts without having to further explain these taken-for-granted phrases, due to the normalised character attributes given to a person with cancer by others (Ellis, Blanke & Roach, 2015). He then, challenged this normalised speech with a single statement as a person with cancer, which contradicts the typically allocated stoic attributes, hence advancing the discussion surrounding the cancer narrative about those living with the disease. The use of intertextual themes and relations to existing speech or concepts, can act as trigger towards challenging or moving away from traditional conceptualisations of the cancer battle and victimship.

As seen, Steve developed this social dialogue of strength, heroism and early death through borrowing meaning from existing health talk and exposing the reality of how an individual can actually feel about having cancer, hence changing the depiction of the stoic 'cancer patient' (Leshan, 1989).

It is important to note the journalist discourse and lens used by Steve when questioning the status quo about the conceptualisation of a person with cancer as being inherently strong once a diagnosis is received. Being addressed as a 'brave' or a 'fighter' are typical terminology and views accepted by both society, medical staff and even charities (McCartney, 2014) and therefore patients who are new to serious illness experiences, may not think to consider or question how they are seen to be of importance, especially within the early stages of being diagnosed when an individual must adapt to physical and psychosocial changes (Groarke, Curtis, Skelton, & Groarke, 2020). It is likely that in certain ways, Steve's perception differed from the average 'cancer patient' as his journalism experience most likely facilitated his ability to question a socially accepted norm or taken-for-granted health narratives such as 'bravery' and 'fighting battles' as a patient. Although Steve would have needed time to adjust to the diagnosis, his questioning of health processes and socially accepted cancer views and language was not typical of cancer storytelling that heavily describes challenges or emotions related to the journey (Frank, 1995). Instead, with his contribution to questioning well-known intertextual themes in cancer (battle and stoicism), this can be seen to provide another layer to storytelling for the purposes showing audiences to critically assess imposed social views and concepts against their own true feelings about their illness experience as an individual.

The openness about maintaining his identity, sense of self and willingness to continue to live his life as normally as he possibly could, was vital in not allowing himself to be socially or mentally affected by the cancer. As a result, the ability to control the changes brought about by the cancer and its treatment prevented the notion of being bound to the cancer or held by it as its 'victim'. However, the importance of how the media addresses people with cancer was addressed by Steve when correcting the BBC's use of language about his life after the cancer diagnosis:

> *I was on Victoria Derbyshire and they ran a call on the bottom saying you know 'terminal cancer' and I didn't realise that, obviously I'm on air and I can't see myself. When I go off, I thought that's a bit wrong really coz you now, I might have weeks, I might have months, I might have years, I might have a normal life span you know, all these things are possible.* (S: Int. RB).

Addressing the use of 'terminal', which was used incorrectly by the programme, was another example of Steve questioning the stigma associated with a certain area of cancer, with the previous being stigma attached to preventing cancer-related hair loss in men and, the second being the social stigma attached to the diagnosis of cancer which insinuates death occurring very soon. Explaining that he

might have 'months', 'years' or a 'normal life span' was a subtle way of educating the public and broadcasting platforms that the use of 'terminal' to describe someone's health when this is not given as an official medical diagnosis by a healthcare professional, can be a careless and inappropriate statement. This was particularly the case as Steve had not used the word 'terminal' to describe his own life at the time of the interview, nor was he given this official diagnosis by his oncologist. Additionally, he was actively having treatment to try to halt progression of the cancer, that at the time seemed promising with first-line chemotherapy, eventually extending his life by months.

As a result, Steve addressed the social issue of being seen by a 'victim' by others which was implicitly reflected when being addressed as having terminal cancer. Essentially, this example demonstrated judgements made by others when a cancer diagnosis is disclosed, showing the issue of being unaware or mis-informed about the various cancer prognoses and the stigma that those with cancer tend to die soon and cannot survive at all. Experiences of being judged for appearances and for the impact of a cancer diagnosis was therefore helpfully deconstructed with the support of prognosis facts and personal psychosocial experience of dealing with treatment side-effects.

5.4.3 Holding on to Identity

The discussion of personal and social reasons for preventing hair-loss in itself had opened up a discussion between Eddie and Steve surrounding the social acceptability of male prevention of alopecia during cancer. Steve noted that he was made to feel different about his decision to undertake cold cap treatment:

> *I think women have many more options with head wear, had gear they can wear, it looks more natural and all the rest of it. But what was weird was the ladies receiving their cancer treatment in the same room- there were some very funny looks being passed across as if to say hang on a minute, isn't that for us?* (S: Int. 1)

This treatment was only seen to be for the benefit of women, putting forward the notion that hair-loss is only a social and emotional issue for women and not for men, as it is more acceptable for men to be bald (Dua, Heiland, Kracen & Deshields, 2017). Hilton et al. (2008) found that only women tend to be encouraged to prevent or disguise cancer-related alopecia. As a result, Steve's sharing of hair loss therapy aimed to tackle social barriers surrounding the acceptability of men seeking to keep their hair. This was done by creating dialogue about the socialisation of physical attributes such as hair and potential prejudice that a man may face because of their gender when wanting to keep or maintain it.

As well as sharing his own personal thoughts and experiences on the potential of losing his hair, Steve raised the important issue of the need for men to undergo such therapy without judgement. In making a sarcastic comment about being vain and wanting to keep his hair; *it may be because I'm a sort of*

typical vain Radio 4 presenter…, this uncovered that there was in fact a deeper issue than physical appearance. This being that the impact that the presence of no hair can have upon an individual trying to maintain their sense of self even through a drastic change and phase of life (Radley, 1994). Although facing some prejudice, Steve demonstrated that it is acceptable and normal to want to maintain one's social image and self-concept, which was what he promoted to his listeners through his own reporting and confidence to admit that the preservation of his hair was important.

Aujoulat, Marcolongo, Bonadiman and Deccache (2008) describe the effort to control the psychosocial effects of a disease and treatment as empowerment. Steve's behaviour and efforts to maintain his hair was reflective of 'holding on', also known as separating identities to differentiate oneself from the illness. With Steve having to adapt to the changes that came along with the cancer, his active effort to 'hold on' to his known identity would therefore allow him to also hold onto previous self-representations that were a part of his self-concept.

5.4.4 Cancer as an Independent Entity

Demonstrating the dynamism of the illness to listeners was achieved by anthropomorphising the cancer which in turn, showed the struggles that Steve faced with it, to the point where it was considered an independent entity; uncontrollable and unpredictable:

> *But the problem is, it is as they say, progressing in the liver and er as my- the amazing Dr Starling said I'm afraid it's on the march, it's determined to get on with things.* (S: Int. 6)

Providing human-like qualities to assimilate the cancer's 'behaviour' suggested a living being described in one of Steve's many reports in the media, in which he used his experiences and information from healthcare professionals to analyse the possible subsequent moves of this 'being'. A good example of this was when Steve was informed that he was unable to take part in a clinical drug trial that he had hoped to due to his blood tests not meeting the set criteria for admission. It was explained that if he were accepted onto the trial, he would be subjected to a 28-day treatment-free period for purposes of ensuring validity of drug efficacy. Steve applied a number of metaphors to describe the speed and progression of the cancer. Providing these metaphorical 'actions' reinforced the conceptualisation of the cancer as a being:

> *…the people who are doing the trial wanna know what they're measuring. Is it at a 28 day wash-out period and in that 28 days, is my cancer going to be sort of doing the knitting, or is it going to be going rock climbing? If you ought to put it that way and er at every opportunity, especially in my liver it's rock climbing, not knitting (laughs). So, there's a risk in 28 days, that some nasty things might happen.* (S: Int. 13)

Steve attributed humanistic activities to the cancer, and this was a narrative technique that aided the audience's understanding about the possible consequences that could occur when undertaking a 28-day treatment-free, wash-out period. The use of metaphor is arguably more easily understood than technical explanations (Laranjeira, 2013). Therefore, at certain times within the interviews, metaphors were used to facilitate the understanding of medical concepts, as opposed to explaining these with technical and clinical language to the audience.

This compares to other journalists' narratives of cancer in the media such as British television dramatist and journalist Dennis Potter, who in his last interview, famously named his cancer as Rupert (after media tycoon Rupert Murdoch) stating, *I would shoot the bugger if I could* (Channel 4, 1994), which demonstrated his strong dislike and frustration of the cancer. The differences in use of anthropomorphising an illness not only highlights the difference between different journalist's perceptions of cancer but also highlights the matter of context and the extent to which journalists may choose to personally address the existence of their cancer as a separate existence, or not. For Potter, comparing his cancer to someone who he did not like showed his anger and dislike towards the cancer. However, Steve's use of anthropomorphism was done to complement the amalgamation of professional reporting and personal storytelling, keeping his audiences in mind to ensure that they would understand clinical concepts easily through imagery. Therefore, it is worth noting that use of certain intertextual themes (such as humanizing a cancer) may be dependent on the context and purpose of a journalist's cancer narrative (recurring interviews about a cancer journey, or a single end-of-life reflective interview).

Medical jargon was also avoided by anthropomorphising the cancer, thus helping listeners to understand complex medical possibilities related to cancer growth or inhibition of growth. These concepts that were portrayed through imagery were easier to identify, for generally interested, non-medical expert radio audiences. The use of metaphor to represent the dynamism of the cancer (*rock climbing* & *knitting*) provided clarity upon the possible trajectories that the cancer could take during a prolonged treatment-free period. Therefore, the dichotomous image of activity created by the actions 'rock climbing' and 'knitting' can be interpreted as the cancer as either progressing at a fast rate or slow rate.

Tate and Pearlman (2016) argue that metaphors help us to make sense of difficult and foreign concepts that we may not be entirely familiar with. This is more so the case when there is 'conceptual unfamiliarly' such as situations relating to serious illness. As such, metaphors such as those provided by Steve facilitated accessibility of knowledge of a new or difficult subject matter to the audience.

Additionally, it has been argued that metaphors, in the place of medical jargon, are more effective in explaining cancer symptoms and the next stages of the disease (Laranjeira, 2013). Steve even acknowledged that personification of his cancer was used by his oncologist:

> *…(it's) progressing in the liver and er as my- the amazing Dr Starling said I'm afraid it's on the march, it's determined to get on with things. So they regarded almost I think a personality (laughs), which I never had but they sort of do.* (S: Int. 6)

Metaphor use within the context of cancer and healthcare does not only aid patient understanding of clinical phenomena but also strengthens the patient-practitioner relationship and communication, such that this can act as a facilitator for patients to make effort to understand their treatment regime and enable them to become more involved in their treatment (Casarett et al., 2010). This proposition by Casarett and colleagues is applicable to the context of Steve sharing experiences and factual information about the cancer in an accessible way, which could ensure that audiences were kept engaged through the use of easily understood concepts. In effect, such easy and useful metaphors can compel listeners to return to the next interview episode in the series. One anonymous listener who called into the PM show supported this notion.

> *Your interview was compelling listening and it really helped hearing an articulate, intelligent person expressing how they feel when presenting with terminal cancer, with similar thought and feelings to those dad would have had.* (A: Int. 3)

It is also important to acknowledge that Steve did not necessarily employ metaphors within his reporting to aid his own understanding of medical concepts, which is something that is typically reported as providing a way of meaning-making for the individual (Kövecses, 2003). As an intelligent journalist who was always able to grasp difficult-to-understand information, Steve understood the clinical aspects of the cancer and his care which was noted by his oncologist:

> *He had this exceptional ability to take really quite complex information in a short space of time and contextualise it and come to his own assessment which was often absolutely spot on. In fact, he'd appraise things in the same way that a medical scientist would, which often always astounded me.* (O: Int. 21)

The use of these types of dynamic and anthropomorphic metaphor in order to engage and interest listeners indicated the continued use of his reporting techniques in reaching a wide audience with information that can be clearly understood by anyone with any background. Even though Steve reported personal accounts and experiences of his cancer, he effortlessly used his journalistic skills to summarise complex situations into bite-sized points (in this case using easy to understand metaphors).

This helped to present the main points of interest via a form of story-telling that was not as obvious or typical of formal broadcasting, helping to create a balance between intimate and factual reporting.

5.4.5 *I'm* [not] *at war with anything*

Another prominent metaphor used by Steve was that of warfare in the context of dealing with serious illness. Warfare metaphor is one of the most commonly used metaphors to illustrate cancer perception and thoughts after diagnosis and treatment experience (Demmen et al., 2015; Hauser & Schwarz, 2019; Sontag, 1978). As such, this genre of metaphorical expression relating to illness experience such as fighting a war has become conventionalised overtime and a normative concept in health dialogue, where it is difficult to avoid in conversation about cancer, even if it does not adequately capture the true experiences of the individual and their perception of cancer (Gameiro et al., 2018). This notion was reflected in Steve's use of warfare metaphor however, he did not refer to as feeling to be in battle against his cancer.

> *I don't feel remotely brave. Honestly, I don't. I'm not doing this out of a sense of kind of you know fight the good fight. I don't I don't I'm not even sure I feel as if I'm at war with anything. It doesn't feel like, I know it's a bit of an alien but it's me. I don't, I don't feel that I'm, I don't even feel that I'm battling something.* (S: Int. VD)

Steve did not see his illness as an opponent, or an enemy as there was no sense of war present. However, the illness was addressed as an 'alien' which effectively helped communicate the perception of a foreign body and referred to a sense of confusion surrounding the cancer's origins and existence. In effect, this suggested the cancer to be an unknown living entity within Steve's body. This contrasted the typical expression of 'invasion' of the body, which is an expression typically used to describe the existence of the cancer (Sontag, 1978). This view draws parallels with propositions by Miller (2010) and Granger (2014), that using violence metaphors in cancer discussion, positions the individual and their illness as opponents, or as emphasised by Sontag, as 'enemies'. This is something that Steve avoided by actively denouncing an outlook of being in *battle* with his cancer. Hence, affirming his actual bodily experiences by stating *it's me*, which demonstrated his preference to ground his experience and existence in the reality of his physical being and self-concept, as opposed to feeling 'invaded' by an illness that has taken over his body.

Metaphors were used for two purposes; for the benefit of the audience, when explaining complex clinical concepts and for personal experiences that required further imagery for understanding and relatability. At times, metaphors were also helpful to demystify a confusing experience which helped to aid Steve's personal meaning-making of the event. Making use of the typical metaphor of war to describe the cancer experience was acknowledged to be a conventionalised way to speak about living with cancer. However, by stating, *I'm not even sure I feel…*, indicated Steve's autonomous thoughts

about his cancer, uninfluenced by the normative way of perceiving cancer as a 'battle'. According to Sontag (1978), warfare analogies inherently create a negative and stigmatic image of cancer which can lead to maladaptive thoughts and coping. Steve's avoidance of warfare with a realistic outlook and active coping indicated that this may have helped his ability to adjust to the effects of the cancer by avoiding the added distress of the presence of an 'enemy'. As a result, he continued through the journey with investing his time and energy in finding treatment as opposed to fighting a 'battle'.

In addition, as Steve did not feel that he was in 'battle' with his cancer, may shed some light about his conceptualisations of the cancer. As highlighted in earlier interviews, *at no point did I feel the diagnosis crushing me,* which indicated his awareness of the cancer's presence. This awareness did not result in the strain of having to 'fight' with the cancer. As such there was a high degree of awareness about the possibility of having cancer and he rationalised his illness experience, *for me I think it is a lot easier to deal with in many ways… in some ways you know I've found it clarifies things… it's like being given notice.*

Contrastingly, there were times when Steve purposefully referred to the term 'battle' when dealing with the aggressive state of his liver:

> *If on the other hand, the battle if you like between my liver and the rest of the world, has improved, then there's nothing I'd like more than going home…* (S: Int. 20)

Within one of the very last interviews, when exploring end-of-life living arrangements (5.6), there was still the sense of not being in 'battle'. However, Steve made use of the word 'battle' as means of normative dialogue enabling the audience, without much effort, to grasp the idea that there was a major issue with his liver and that this was a significant and influential factor in planning where to spend the end of his life. The phrase, *if you like* supported the notion of conventionalised war and cancer speech, which reinforces that certain metaphors are more cognitively accessible and helpful in aiding understanding of experiences and ideas (Gameiro et al., 2018). Therefore, such metaphors are still used by individuals even when they do not necessarily reflect their true values or perceptions but help to simply describe and portray the essence of a concept in a simple way. In Steve's case, warfare metaphor was used to describe the unpredictability of his liver as opposed to some sort of distress caused by the cancer. Casarett et al. (2010) argue that metaphors can help to avoid medical jargon and at times provide a much clearer explanation about a medical concept more so than a formal or clinical explanation, which may be difficult to understand and non-relatable.

Had Steve not used the metaphor of 'battle', he would instead have needed to provide a biomedical explanation of the issues associated with his liver, which was extensively covered earlier on within the

same interview*; …they worried that the morphine, the morphine is also managed by the liver and there comes a point when… the liver fails to break down the morphine at which the morphine's effect become all the more significant.* In order to avoid repetition and further confusion about the state of his liver, such as growth of metastases and chemotherapy-related depletion, the use of metaphor of battle helped to effectively demonstrate the fluctuating health of his liver along with the unpredictability in the current and future state of it. This was because it was unclear when it would remain stable enough to allow Steve to continue to take pain medication. Therefore, the use of the warfare metaphor in this context appropriately captured the complexity of the health of his liver and not necessarily for the purposes of representing the psychological relationship with the cancer and its side-effects.

It is worthwhile acknowledging the various other types of journalist illness stories that preceded Steve's cancer reporting journey that had drawn up on intertextual themes such as battle and enemy for different reasons and contexts other than those shared by Steve. Contrasting accounts can be seen by journalist and writer Dennis Potter and writer and critic AA Gill, who both shared their views on having terminal cancer close to the time of their death. Both writers spoke of politically-charged topics and the frustrations related to having cancer, and the misfortunes that came with it. Potter portrayed anger towards his cancer by comparing it to being a hated presence in media (Rupert Murdoch), which he would have liked to have 'shoot'. Whereas, AA Gill pointed out that the real 'battle' was to be prescribed immunotherapy on the National Health Service where one could not afford this treatment privately: *more life spent on earth but only if you pay* (Gill, 2016). Gill and Potter's last accounts were similar in mode, exhibiting aggression and frustration towards the cancer, and challenges that arose with it. Overall, providing a cathartic interview and newspaper column invited audiences to hear candid emotions, treatment struggles and the reality of an early death as *old men who think they're going to die anyway, aren't effective activists* (Gill, 2016). Following on from Gill's comments, Steve had in fact spoken up against the unavailability of immunotherapy when discussing NICE cancer treatment decisions with its Chief Executive on air (5.3.3). Although Steve had limited scientific evidence to draw on during his advocacy for Nivolumab (immunotherapy), he still demonstrated the activism that Gill noted many men, even within media, did not carry out. Therefore, although Steve did not share Gill's way of speaking about his cancer in 'battle' terms, he advanced the conversation about treatment for older men but in a different context, which was for practical purposes, so that people with OC could benefit from an extended life where possible.

This comparison shows that Steve had a highly particular trajectory for his reporting which encompassed the exploration of institutional and technical processes involved in diagnosis, treatment and arranging end of life care. Similar to this, Victoria Derbyshire also adopted a journalistic and storytelling stance for her video diaries about her cancer treatment, which similar to Steve's reporting,

presented pragmatic and reflexive accounts of the breast cancer treatment process in a step-by-step fashion. However, more emotional accounts were seen at the end of the chemotherapy where this marked the end of her struggles. Again, similar to Steve (5.5), Victoria detailed how the real 'battle' was with chemotherapy and recovering from its effects. Although the diary videos were pragmatic and informative about breast cancer, it was seen that when interviewed about her experience, a year after treatment was completed, she described the cancer diagnosis as *a colossal fist crushing me* (ITV, 2017). This phrase, if looked at in accordance to Sontag's propositions, would position Victoria as a victim (being 'crushed'). And so, even though both journalists shared their journeys on a practical and step-by-step basis, they had very different outlooks about the existence of their cancer. Consequently, what differentiates Steve's and Victoria's reporting of cancer as journalists, is the perception of battle and victimship. In effect, Steve's uniqueness (in comparison to Denis Potter, AA Gill and Victoria Derbyshire) of conceptualising what his cancer was not (a battle or an enemy), is what provided an interesting basis trajectory for his broadcasting of his detailed diagnosis and treatment journey.

5.5 Buying Time

5.5.1 *A couple of lucky breaks*

There was an indication to have some control over an early death and gradually, the audience was shown the struggle in Steve's personal efforts to extend his own life. This is contrasted with the perception of having 'luck' on his side, as a healthy individual who never had to think much about the trajectory of his life. However later on, Steve referred back to the concept of 'luck' as a returning phase which helped to facilitate his treatment; something that he addressed as being a *lucky break.*

> *I think since the whole cancer thing where it began, I've had a couple of lucky breaks. I got into the Marsden, I've got a great team of people you know looking after me erm but actually you know the first line of chemotherapy eventually failed. The second line didn't fail but was really hard to tolerate. Especially at the back of radiotherapy, which again appears to have done its job but was very, very hard to tolerate.* (S: Int. 17)

Steve described the multiple treatments and hurdles experienced in an effort to control his health so that he could live longer. However, he did not acknowledge his own actions for treatment which, had in fact been influential in reaching significant points in his journey, such as referral. An example of this was when he had directly contacted The Royal Marsden as well as his local hospital to speed up the process of appraising his case (5.2.4). While attributing his success of gaining treatment from the Royal Marsden as a product of 'luck' could be one explanation (*I've had a couple of lucky breaks*), it was clear that his active information-seeking behaviour, which was followed through with actions, demonstrated that he, himself had a significant impact upon the progression of his case, after taking

responsibility for his own healthcare, also known as taking on the 'active patient role' (Forsyth, Maddock, Iedema & Lassere, 2010), as discussed earlier (5.3.1 & 5.3.2).

The concept of 'luck' acted as a way of meaning-making for experiences, helping Steve to explain the existence of the cancer as something brought about by an external source beyond his control, which similarly was also the case for the positive experiences in his life as explained earlier (5.2.1). The concept of luck, although abstract, was seen to ground Steve's perception of the origins of the cancer into something tangible, or as a common metaphor used to make sense of something that is beyond human control, and a matter of good 'fortune'.

It is also useful to consider whether this meaning-making stemmed from Steve's profession as a journalist whose job was to make sense of events and educate the public (Thompson, 2019). However, acknowledgment of 'luck' and philosophising about the influence of this upon his health, did not undermine the carrying out health and participatory behaviours; this behaviour itself juxtaposed the perceived impact of 'luck' upon his health, as he was able to influence the treatment journey to an extent and at times, the speed of this with his own actions.

By contrast, there were significant events that were purely attributable to chance and Steve's 'luck'. This was the case when Steve was finally accepted to take part in a prestigious and promising clinical trial, even though his albumin levels were clinically-unreliable in the week leading up to participant recruitment.

> *She* [clinical nurse specialist] *says 'no no no fantastic, you've been accepted for the trial, it's all full speed ahead, we can do, we can get started tomorrow erm and so and also, you've been randomised' (clears throat) and so everyone gets Nivolumab and half get this other drug. She says, 'you've been randomised into the group that gets both drugs'…. suddenly, it feels like it's a huge break of amazing good fortune.* (S: Int. 17)

Steve was keen to take part in a new form of treatment (immunotherapy), which was propositioned to be more effective for middle aged men. When accepted on to the trial and that too with allocated doses of the immunotherapy and another drug, once again, Steve's strong belief of 'luck' was echoed once again.

5.5.2 The Pressure of Time

'Buying' (gaining) more time to live through treatment was at the forefront of Steve's priorities. He felt the passing of time to be more pressurising as the cancer progressed. Therefore, the 'war' (5.4.5), was in fact a war against time and not the cancer itself, as gaining more time to live enabled more time to find effective treatment to delay the development of the cancer, with the hope of potentially

extending his life. This was a continuous cycle that Steve faced in finding effective treatment. Finding ways of 'buying' time was stressful as was competing with time to extend his life. Finding successful treatment provided a way of controlling time by stopping cancer growth and extending his life. On the other hand, running out of successful treatment options meant that there would be no other means of buying more time. Although the worry of an early death was present, it was made clear that he was not affected by such a serious prognosis of the likely outcome of an early death.

Steve mentioned that he continued to feel the pressure of time and this began to affect his mental health. This was shown when Steve had to miss a week of chemotherapy (Paclitaxel) due to infection:

> *…. there's a very tangible sense of the way, of pressure building up. I feel it anyway, when you can't have treatment. Because in the back of my mind is the idea that the cancer is kind of gonna be advancing, it's gonna you know, it's gonna get away from you somehow. Get out from under somehow and so, even a week's delay, which first of all you kind of think, oh it's a week of…. Actually, psychologically, it starts to get into your head.* (S: Int. 9)

The cancer continued to be addressed as a moving and independent entity (5.4.4) where the lack of control, as a result of missed treatment, gave it the opportunity to develop and progress. The effects of the cancer's 'movement' were more amplified when treatment was temporarily halted because Steve felt that he was no longer doing anything in that time to stop its progress. This therefore created worry and stress which had the potential to affect his recovery at times. The psychosomatic effects of treating the cancer were experienced at later stages of the treatment phase, where the stress of passing time and managing treatment manifested into physical symptoms and distress (additional to the cancer symptoms and also worsening these):

> *So it's quite clear to me that the tensions starts rising and I would've discussed this before but I find stress now produces a physical reaction. It actually produces a physical reaction. It actually produces pains in my stomach and my oesophagus.* (S: Int. 17)

Dealing with stress was present from the very beginning of the journey, when Steve felt the pressure to rapidly escalate his diagnosis and treatment, having been diagnosed at stage four of the cancer. However, the experience of stress became more prominent in the treatment phase when there was realisation that the cancer would be progressing as more time had passed by, without effective therapy and Steve was wary of this. He was able to manage the stress but reasons for doing so differed as these related to his actions, internal sense of control and sense of time passing. Initially, the stress was mostly under control and there was no mention of the psychological impact of this earlier as Steve felt that his speeding up of processes and taking part in treatment meant that action was actively being taken for the benefit of his body and extending his life. As some satisfaction was felt from physically making

an effort to slow down the rate of cancer growth, this helped to decrease feelings of stress. However, at the stages of experiencing low albumin levels, pneumonia and a heart scare, treatment was brought to a halt each time which was more stressful than the existence of the cancer itself. This was due to a sense of *doing nothing* (S: Int. 9) and giving a break in treatment, which meant the cancer would *get out from under* (S: Int. 10). Steve's perception of the cancer's development depicted that although PTG after a diagnosis can be experienced, it is still a continual path of growing and over-coming obstacles such as delay in treatments in order to maintain a positive psychosocial transformation to help better cope illness. Hence PTG can be seen not to be a permanent state or outlook, but an ongoing process of maintaining one's trajectory to overcome self-limiting and external obstacles.

When referring to his life successes and previous good health, Steve attributed these to 'luck' as opposed to his own efforts and dedication towards his work as a journalist. This was stated frequently within the interviews (5.2.1 & 5.5.1) and as the series progressed, the means to actively prolong his life as much possible was uncovered in the partaking of multiple treatment regimens (government-funded and privately funded). As such, there was a shift of replying upon 'luck' to relying upon his own active efforts to influence his treatment trajectory. This was summed-up in one quote.

> *…the only way, sensible way of thinking about this I think, is to maintain your quality of life for as long as possible and buy time* (S: Int. 5)

However, with the concept of time and pressure that was constantly echoed throughout the interviews, Steve advocated the importance of focusing on one's QOL but at the same time extending life where possible. It became more evident that gaining more time to live was the primary focus when Steve admitted his feelings about the passing of time; *I'm getting a bit concerned about the passage of time; missing treatment is kind of frustrating…. you kind of feel as if the cancer's gonna get out from under* (Int. 10). This demonstrated that the pressure of finding more time to live was more stressful than 'fighting a battle' with cancer, which he did not believe was there in the first place. Instead, the real 'battle' lay with fighting against time in order to then gain more time to find effective treatment which could allow him to live longer. And so, this continuous cycle of trying to live longer which was experienced throughout prescribed and experimental treatment, portrayed the actual 'battle' that Steve faced.

During the journey Steve assumed responsibility of extending his own life and wanted to take charge of his health through active participation in jointly-agreed treatment with his oncologist. Being aware of the possibility that treatment options may no longer be available, demonstrated an awareness of time pressing which was equally complemented by his self-awareness of his own concerns (Duval & Wicklund, 1972), thus helping him to frame a realistic perspective on how to manage his health and

priorities. Adopting this type of an awareness outlook assimilates mindfulness, consequently helping an individual to frame a situation using 'realistic optimism' (Schneider, 2001), where Steve was optimistic about extending his life, facilitated by his ability to take part in treatment but also maintain a realistic view of outcome. This frame of mind also reflected that of the coping technique of 'fighting spirit' (Tschuschke et al., 2001), one of the subscales used to measure coping strategy in cancer diagnosis (Tschuschke, Denzinger & Gaissmaier, 1996). Adopting a 'fighting spirit' has been suggested to be a type of realistic optimism, in which individuals who tend to address failures of their treatment cope better with their experiences of cancer compared to those who avoid its existence and effects. For example, adopting fear-avoidance behaviour and denial (Cordova et al., 2003; Spiegel, 2001). 'Fighting spirit' was a concept that was demonstrated by Steve's actions to continue with treatment, even when faced with multiple obstacles, in order to be accepted onto experimental treatment and dealing with ineffective or failed treatment.

As echoed by Tedeschi and Calhoun (1995) mental growth or transformation after trauma entails optimism, which is associated with an active and problem-focused style of coping or way of dealing with difficult situations. Typically, this would allow for the avoidance of unproductive feelings of complete distress that can be triggered by stress. This may illustrate how Steve was able to continue on with failures and obstacles in his treatment journey and why he displayed more of a practical and balanced outlook, rather than a negative or heavily emotional demeanour. As proposed by Tedeschi and Calhoun, such an outlook and behaviour strongly indicate positive growth after a trauma such as a cancer diagnosis or continual sub-traumas such as treatment failure in extending life. However, it is important to note that optimism itself is not enough to experience growth (Tedeschi & Calhoun, 1995, p.48). Instead, it is vital that productive behaviours are carried out to facilitate adaptive, rather than maladaptive coping in cancer.

The psychological impact of the stress was also shown when all licensed NHS and privately-funded treatment options had been exhausted. However, Steve decided to continue with the effort of trying to extend his life with experimental treatment in the later stages of the journey, rather than purely focusing on the quality of his life. Research shows that people with end stage cancer prefer to focus their energy upon the time that they have left and manage their current health as opposed to choosing to extend their life (Voogt et al., 2005). A case reported by Kübler-Ross (1969, p.103) showed that a patient refused surgery at the end of her life, which could have helped her to live a little longer and be more physically comfortable. The patient was more comfortable with dying sooner as she had reached a high level of acceptance. In contrast, Steve had declared that he accepted that he had cancer and a shortened life-span, however his behaviour and efforts to extend his life would show, according to end-of-life literature, the opposite of expected end-of-life preferences by the average patient. Shen et

al. (2018) found that nearly 73% of patients prefer comfort care compared to 14% of patients who would opt for life-extending treatment. Going by traditional patient behaviour when diagnosed at later stages of the cancer, patients would accept the lack of treatment options available (Mack, Weeks, Wright, Block & Prigerson, 2010). In Steve's case, it was demonstrated that having acceptance is not linked with 'giving up' on treatment options. This is also echoed by Kübler-Ross in that acceptance does not mean 'acceptance of defeat' and although it can inform a person's outlook that they wish to adopt, it is not a direct influencer of whether one will undergo life-extending treatment or not. This is because other factors may play a directional role in treatment trajectory, for example, having a 'fighting spirit' (Tschuschke et al., 2001) or love for family (Tedeschi & Calhoun, 1995; 2006). In addition, Steve's access to the world's most prestigious gastric cancer drug trials also provided hope with extending his life even though he had the added pressure of time passing by with treatment and infection obstacles.

Acceptance of the cancer and previous ineffective types of treatment did not deter his personal wishes to extend his life with experimental treatment. Having had high acceptance and continuing on with treatment was indicative of resilience, a form of PTG (Lepore & Revenson, 2007). Positive growth after trauma, such as a cancer diagnosis is beneficial when one's perspective is balanced. For example, not having an overly positive or overly negative mind-set of one's health, or life. Excessive hope can lead to expectations (Kübler-Ross, 1969) and when these are not met with a positive outcome, such as effective treatment, can be detrimental to a person's interest to 'keep going' (Reeve, Lloyd-Williams, Payne & Dowrick, 2010). However, if a person has an overly negative outlook, this may affect their willingness to take part in potentially successful or life-extending treatment, or treatment to improve current quality of life (QOL) (Kübler-Ross, 1973). This proposition may shed light on Steve's will to progress with different treatments and explain why after being disheartened by ineffective treatment, did not hinder him from 'buying time', even with the passing and pressure of time. It is however, important to note that a desire to live longer differs with age and treatment preferences, such that younger people are more likely to actively take part in life-extending treatment behaviours even at an end-of-life diagnosis (Parr et al., 2010). Steve was relatively young when diagnosed, therefore his age and intended future experiences with his family may have equally been his influence to 'buy' more time.

Another effect of experiencing the pressure of time was feeling failure against time and of the halting of the cancer's progression. The initial response of relief for missing treatment (due to being ill) was instantly changed by his awareness of the overall implications that this would have in the struggle to live longer.

S: *Missing treatment is kind of frustrating. You feel as if you're failing somehow…*

E: *Is there a sense that you're doing nothing?*

> S: *Well first of all it's a sense of relief, oh fantastic, a week off! No side-effects but then you think you think oh god you know, I really wanna be getting on with it. And there's an underlying concern that if you keep missing treatments, that's what's- I don't know if any scientific basis for this by the way but you kind of feel as if the cancer's gonna get out from under.*
>
> (Int. 10)

Even though the stress associated with staying organised with treatment and dealing with numerous side-effects was present, Steve was prepared to continue with treatment when possible, although he felt an initial relief of having to postpone treatment. The initial reaction to stopping treatment was overcome with his practical outlook as he re-focused his attention to the overall trajectory of his cancer treatment journey and the goal of buying time.

By engaging in treatment, Steve felt that action was being taken to control the cancer. However, when a gap in treatment occurred, the liver was characterised to be an escapee that would grow and develop even within a short amount of time that was treatment-free. Therefore, control over the cancer stemmed from having treatment and a lack of control was attributed to a lack of treatment. This was seen as his own responsibility to the point of feeling to be failing, not against the passing of time but not being able to extend his time by bringing cancer growth to a halt or contain it. Tedeschi and Calhoun (1995) speak about the concept of control to be internalised by the individual, such that a person who had transformed through growth after a diagnosis feel a need to take charge of their health. This outlook and responsibility-taking behaviour is also reflective of the active patient role (Forsyth, Maddock, Iedema & Lassere, 2010).

5.5.3 Hope with Clinical Trials

After all first and second-line treatments had failed to halt the cancer's development, Steve and his oncology care team directed their efforts to experimental treatment. Being recruited onto the immunotherapy (Nivolumab) trial would be a new type of untried treatment that could be beneficial to Steve as there was indication that getting onto the trial would in effect, help make up the lost time as a result of previous treatment delays and failures.

> *It's very hard to get out of your mind what's the underlying disease doing. You know give it half a chance and it's out there doing more than it was before. And erm so, there's pressure to get onto the trial because it's a good thing to do. Everyone's put a lot of effort into it et cetera et cetera and there's also ticking away in your mind, at every little ache or pain that you get, you think ooh! Is that it?* [Laughs] *Fingers crossed it's not…* (S: Int. 16)

Once again, the cancer was conceptualised as an entity with having a mind and actions of its own when not contained by treatment. And so, treatment was used in stopping the cancer from progressing and getting out of control. As a potential form of treatment, a lot of importance was given to the trial where Steve and his oncology care team hoped that he would be recruited onto it. Hope was attached to this trial more so compared to other cancer drug trials that Steve had previously tried to participant in, as this trial was seen to be more promising for those in his age group and biological sex, in halting the cancer progression. This was demonstrated by the sense of pressure that he felt to not allow this opportunity to pass him because the trial was theoretically promising. In the context of cancer, Hagerty et al. (2005) found that after asking for definitions of hope from people, different definitions are given to hope with the most common being that one can still enjoy a good QOL even when life expectancy in uncertain. Another definition uncovered was that there is a chance of a good outcome. In Steve's case both definitions applied, as with the halting of the cancer, a better QOL would be seen as well as a potentially positive outcome (more time to live).

In the effort of trying to get on to the trial, obstacles in Steve's health made him view his life and efforts as unlucky. The concept of luck was once again echoed later in the journey, but now instead of in the context of receiving a diagnosis, running out of luck was seen to be a subsequent issue after finding effective treatment and having good enough health to undergo treatment in the first place.

> *I'm feeling a bit like I'm sort of, seem to be a victim of what you might call Sod's Law! So you know, New Year's Eve, the heart scare. Well, thankfully that nothing came of that, nothing on the front which is great. I was then consented the following day the Tuesday as it were, after I'd spoken to Eddie, I think er to go on the trial. And then the bloody whoops excuse me… then the pneumonia pops up.* (S: Int. 15)

Rather than attributing his health to having a dampened immune system and experiencing the effects of the cancer, Steve had associated his poor health with being unlucky as this had occurred near the time of receiving treatment. Using theory (Sod's Law) to legitimise his perspective of having bad luck echoed to audiences that one may protect themselves as much as possible and adhere to treatment and aftercare guidelines to the best of their ability but things can still not go as expected. Thus, demonstrating the nature and instability caused by the cancer and in the management of it. On a personal level, referring to bad luck as the reason for his obstacles was done as a way of making sense of negative event which was similarly framed at the diagnosis stage when feeling to have run out of luck. Having an explanation for bad health still provided an attribution to an external source of control that is 'luck' (even though this is an abstract concept that contrasted with Steve's logical outlook and awareness of clinical issues). Somerfield and McCrae (2000) suggest that providing an explanation or rationalising makes it easier for an individual to cope with failures or unexpected scenarios. Therefore,

explaining unsuccessful endeavours in clinical trials as a result of the lack of luck, had potentially provided Steve with the space to deal with the set-backs that were experienced.

5.6 Death and Dying

5.6.1 *I could pop off at anytime*

Towards the end of the journey, immunotherapy had to be stopped as Steve's liver had begun to shut down and further treatment was dangerous to undergo. As a result, Steve could only have symptom-controlling treatment and was informed by his oncologist that he was officially at the end of his life. This news triggered a process of realisation that he was dying, and death was soon to come:

> *Oh hang on a minute, she's saying so I could pop off at any time. I could be gone in hours, this could be it. I could be gone in hours, this could be it. Erm and I sort of feel, also that in a way, this was the part of the process again, when we discussed it before, I think I said I was always most afraid of. You know that I wasn't sure how actually going would be. And I still don't know how going would be or dare I say, will be.* (S: Int. 19)

In line with Steve's previous dealing of referral and treatment, the lack of control and knowing was what had contributed to the fear surrounding death. Instead, when addressing his eventual death, he discussed the seriousness of the situation with humour (*pop off*) and metaphor (*this could be curtains*) as if to indicate his 'story' that he tended to refer to his journey as, would be drawn to a close shortly. This was one of the first times within the journey where Steve exposed feelings of being scared. Kastenbaum (2000), defined the fear of death as 'death anxiety'. When speaking about being given news of officially being at the end stage of his life, there was no mention of the words *death* or *dying* or even beliefs about what will happen after death (Gonen et al., 2012). Steve's anxiety about death was not about dying itself but about the uncertainty of when exactly his death would occur. Death anxiety has been addressed as being a rational and practical fear of worsening pain and the body's eventual deterioration (Neel, Lo, Rydall, Hales & Rodin, 2015). Therefore, not knowing how one will die and what the experience of dying will be like creates worry, especially within advanced cancer (Lo et al., 2011).

Much research has associated or discussed the presence of, or the lack of fear of death with the spirituality of the individual (Boscaglia, Clarke, Jobling & Quinn, 2005; Puchalski, 2012; Stefanek, McDonald & Hess, 2005; Weaver & Flannelly, 2004). Early work on spirituality was shown by Kübler-Ross (1969) who proposed four quadrants that make up the human life domain (physical, emotional, intellectual and spiritual). Spirituality and the 'spiritual quadrant' is described as looking beyond material aspects of life such as focusing on 'paying taxes', or having houses and cars and instead, looking internally for stability and balance. According to Kübler-Ross, a mature spiritual quadrant

provides a way of dealing with the fear of death or death anxiety. According to this theory, the indication of Steve's lack of acknowledgement of spirituality (as portrayed by the lack of discussion this within interviews) would therefore mean this accounted for his fear surrounding his death. Although Steve did not share thoughts about spirituality, his understanding of, or thoughts about death do not necessarily indicate that were no perceptions on this topic. It is important to consider that he may have had ideas and impressions related to this life domain that were not shared within the interviews for personal reasons.

In addition, Kübler-Ross's explanation of death anxiety simply does not cover the breadth of reasons as to why a person could face fear surrounding death (Abdel-Khalek, 2002; Routledge, 2012; see also Branson, 1975). Steve's practical outlook that was adopted in the very beginning of the journey and maintained throughout, is what created the reasons for his anxiety which included the worry about the organisation of an appropriate living environment and timing of his death. And so, an explanation of an under-developed spiritual quadrant cannot provide a reliable way of determining reasons for death anxiety so that these can be addressed by healthcare staff as recommended by Kübler-Ross (1974). This is particularly so if there is no evidence of an individual having or not having spiritual inclinations to aid their coping. Instead, Kastenbaum's (2000) partial model of 'journey' is helpful in explaining the uncertainty that Steve faced with the timing of his death and how he would die. Fear surrounding this is a rational and appropriate response to have, as the next stages of his health and the time left to live was uncertain. Even though it was known that there was now a limited time left before Steve would die, this was simply not enough information to help him understand the trajectory or events of the next few days or weeks of living.

5.6.2 *Living everyday as if it's the last*

The topic of life was touched upon briefly by Eddie when he asked about Steve's perspective of the traditional concept of living each day as if it's his last and the tool of a 'bucket list' to aid one's last living moments. For one of the first times in the journey, audiences were provided with a very personal view about a topic from Steve, without the back-up of facts, figures or technical explanations. As such, he dissected down the expectations of living a 'fulfilling' life through the use of a 'bucket list'; a normative concept in western society (Masterson et al., 2018; Portman, Thirlwell & Donovan, 2018). This was a similar move to steering away from over-used dialogue, language and thought surrounding cancer and end-of-life living, which was also echoed about warfare imagery (5.4.5) created through the use of metaphor (Hauser & Schwarz, 2019; Sontag, 1978):

> *Well I don't… if you're told right literally it's any day, I dunno quite how you go on about living everyday as if it's your last. And what do you do? You go- is it where you empty your bucket list? I don't know. I literally don't know what you'd do. I think what you're looking for or what I'm looking for in that statement about using*

> *everyday as, as if it's your last, there's not so much meaning to that statement. It's more kind of being able to relax, being able to spend time with friends you know. It's, that's what I look towards I think. A lot are looking towards a list of things.* (S: Int. 20)

Steve did not have much consideration on how to live a single day as his last day alive and therefore was not convinced by the idea of a 'bucket list' as this reflected the need to carry out prescribed activities before death which could seemingly occur the next day. He discussed the idiom metaphorically to conceptualise his view of the lack meaning that is attached to a 'bucket list'. 'Emptying' a bucket list suggested that nothing meaningful was left afterwards of carrying out an item on the list. Completing the activity was done for the sake of fulfilling the list which would then meet the expectation of living the day by carrying out an activity. He reinforced that a lot of people lived their lives by the confines of a list which in itself, as a concept, lacked purpose and fulfilment. Instead, he indicated that meaning-making was important and necessary, which was not necessarily created by doing new things, but enjoying and cherishing taken-for-granted aspects of what one already has in their life. Familiar and comfortable activities such as relaxing and spending time with family and friends had existing meaning attached for Steve which were also activities that were a priority for Steve throughout his cancer experience as shown in the difficult and unpredictable journey of finding effective treatment to extend his life in order to have more time with family (5.5). A recent study by Larsen, Schultz, Mortensen and Birkelund (2019) looked specifically into living with OC and found that carrying out familiar activities gave individuals a better sense of control and comfort when having to adjust to new life situation. This may explain why Steve did not find the need to take part in new experiences at this stage in his life.

Although a 'bucket list' or recognising 'unfinished business' can be helpful to allow cancer patients in prioritising aspects of their life if they haven't already done so (Masterson et al., 2018), it is unlikely that these patients will have the energy (or money) to carry out new and exciting activities, therefore not making a 'bucket list' practical. In addition, experiences which lead to meaning-making of the world or of the individual (self-growth or life-meaning), facilitates better psychological adjustment, helping the individual to adapt to a phase of life, for example, palliation (Park, Edmondson, Fenster & Blank, 2008). This may explain Steve's transition to acceptance and awareness of an early death that could happen 'any day', which occurred through his meaning-making experiences and spending time doing familiar things as opposed to trialling newer things that lacked inherent long-standing meaning. Additionally, Steve's thoughts echoed the idea of living in the present rather than planning forward which was a way of addressing the limited time left to live and the unpredictability of when death would occur.

Steve's consideration and appreciation towards simple and everyday activities and the current environment around oneself, was demonstrative of mindfulness, which has been seen to form a way of adapting and adjusting to the reality of one's situation (Adler & Fagley, 2005). Being mindful of one's own current situation can act as a coping strategy to gain satisfaction with or in a person's present experience (Carlson, 2016), and Steve had adopted the outlook of appreciating current events and things in his life (5.2.1), which echoed a state of mindfulness helping to keep himself balanced between living as normally as possible and accepting the reality of dying 'any day'.

Kastenbaum (2000, p.248) portrayed the importance of continuing to 'be one's self' at the end-of-life by not feeling the need to follow prescribed models of how to live or living when dying as this does not facilitate purpose or meaning for the individual (Park, Edmondson, Fenster & Blank, 2008). Case studies reported by the author showed that individuals who created their own models on how to live their last few days were more satisfied with their experiences. Living by traditional models such as having a 'bucket list' or being expected to try never-tried before experiences could be counter-productive to the individual's coping with their eventual death, as these activities are not in line with their priorities or beliefs. Therefore, Steve had adopted the appropriate method to adjust to and cope with the process of dying, in line with his own expectations, which helped him psychosocially at the end stages of life. This also explains why the idea of a 'bucket list' was seen to lack *meaning* as this did not meet his perception of living well at the end-of-life.

5.6.3 *I certainly wasn't gonna give up*

Another important question that Eddie has asked brought to light Steve's feelings about his struggle with treatment and luck of success with immunotherapy, which was regarded as potentially the most effective treatment for Steve.

> *E: You worked so hard to get onto trials and you've been optimistic and looking to the future, and a lot of it's been about what treatment might be available and just at the end of last week, that was pulled away from you and I wonder, and I realise all joking aside that in your sometimes drug state, you might not be able to, to think as clearly as you might want, but I just wonder how was that for you?*
>
> *S: Well I I I, it was, if I say this, please don't just believe me, erm I took it rather as I had taken the initial diagnosis, which is rather sort of I suppose, fairly phlegmatic kind of way. And I think I mean I'd I'd remembered our first sort of conversations about this. I'd kind of accepted at some level or other that the outlook was not good for me in the long, you know, in the medium to long term… of course you live with hope and you do your best and you don't know you know. I didn't, I certainly wasn't gonna give up and all the rest of it. But I was left with, this left me feeling, I didn't feel you know a collapse of (inaudible). I didn't think, oh well! That's it!*
>
> (Int. 19)

Once again, Steve demonstrated himself to be someone with high acceptance of an early death without the loss of hope as he continued to to undergo potentially effective treatments and live for as long as possible. He reinforced here to Eddie that from the initial cancer diagnosis, he was very aware of the long-term projection of his health even when trialling treatments to extend his life. This was something that Steve remembered and had become a sustained perspective which created the balance between his hope for successful treatment and the reality of his situation. Therefore, making it easier to an extent to accept failed treatment, due to the initial understanding and acceptance of the stage of cancer diagnosed at. This was a contrast to Kübler-Ross's theory of the stages of grief as with his emotional and psychosocial transformation in the journey, acceptance was the first stage and was maintained even in the transition from effective to failing treatment experience.

When telling Eddie, *please just don't believe me*, Steve clearly remembered the details of the cancer diagnosis and his health forecast from the initial diagnosis appointment enforced that he had a sustained of cancer acceptance and his 'phlegmatic' attitude towards an early death had not changed even though he was equally hopeful for living longer. Remembering details from the very first diagnosis appointment is not something that most patients tend to remember due to the initial shock of receiving a diagnosis (Cathcart, 2015). This notion was also confirmed by the Macmillan nurse guest on the PM show who echoed that patients in shock rarely remembered what was told to them by their diagnostician, *people will be sitting down in their doctor's surgery in the clinic and the doctor says they've got cancer… they freeze.* (MN: Int. 1).

The fact that Steve was prepared beforehand of his diagnosis appointment and had immediately accepted his diagnosis, reinforced the legitimacy of his continued attitude of acceptance, even up until the end of all treatment and afterwards with the official palliative timeframe diagnosis. Schoolfield and Orduña (1994) describe denial as a 'buffer' to process information related to a terminal diagnosis, thus providing time and space for the individual to accept or address their shortened lifespan. In Steve's case, he did not require this time to 'buffer' his thoughts about the change in his health as he had already suspected that he had cancer (5.2.2). As a result, he had mentally prepared himself with his own research and expert information prior to the official diagnosis to prepare him for the journey of treatment (5.2.1). This understanding and awareness that continued on into the journey, even during successful periods of treatment, meant that a 'buffering' period was not required after receiving the news of nearing death. Hence, the reoccurrence of a 'phlegmatic' and accepting-of-death attitude after all treatment had failed, reflected the genuine sustained acceptance of eventual death was present consistently throughout the journey.

Another important reason for the continued acceptance of an early death was the realisation that he had a good and fulfilling life, which provided satisfaction of having gained valuable life experiences

that could be looked back on. Using an existential perspective, Kastenbaum (2000, p.200) stated that "the way in which we die has much to do with the way in which we had lived." As such, being appreciative of one's life therefore diverts despair or terror from the prospect of death. The satisfaction from leading a fulfilled life provides the individual with solace for their loss of life, making it a smoother existential transition from living without a limited timeframe before diagnosis to accepting an early death.

In addition, another important consideration for realistic acceptance related to the feelings of hope that Steve had when perusing and taking part in treatment. The acceptance that advanced treatments were available to Steve through modern therapy (immunotherapy), private treatment and prestigious world-class clinical trials gave Steve options and a reason for having an optimistic outlook in extending his life even by a few months. Having access to the best possible treatment for OC in the country facilitated the continuation of the treatment journey even with the awareness of an early death. This balanced perspective on acceptance and still wanting to extend his life however was not reflective of the separate transitional stages in experiencing changes of attitudes and perceptions when dying (Kübler-Ross, 1969). Steve had experienced 'acceptance' as the very first attitude and maintained this while also trying to 'bargain', as per Kübler-Ross terminology, for an extension of his life through trialing treatment. Steve did not address his efforts to extend his life as 'bargaining', instead there was mention of accepting the struggle to live longer by*: gambling; [cancer] can't be in inverted commas, cured but can only be managed. You're sort of buying time, you're gamblin- you're buying time.* (S: Int. 5).

Bargaining has been defined to be an attempt to postpone death (Kübler-Ross, 1969; Sánchez, 2005) and there was effort made to postpone death by gambling Steve's limited time by investing this into experimental treatment in the hope of a return of more time to live. Although it is noteworthy to consider that *bargaining* and *gambling* may theoretically serve as the same function (efforts in extending life), the method of doing so are arguably different. According to Kübler-Ross, 'bargaining' implies that one would be reaching an agreement with God or a divine being to live longer which assumes that an external being has control over or has some influence in a person's life. Therefore 'bargaining' cannot be applicable to those individuals who do not have or show religious or spiritual inclinations. However, an attitude of 'gambling' one's resources is a better explanation for those with a practical outlook (such as Steve's) for wanting to extend their life through clinical trials. This is particularly the case in the modern day and age where experimental treatment is available due to more research and technology funding in cancer. In addition to this, Steve's experiences showed that it is possible to experience more than one attitude at a time towards dying. This is something that Kübler-Ross accepted in her companion guide (1974) which was released shortly after *On Death and*

Dying (1969). It was also acknowledged that a person at the end stages of life may not transition through the stages in the depicted chronological order, and as stated by Kübler-Ross, the stages are merely "descriptive, not prescriptive" (Branson, 1975). Steve's adoption of the stage of acceptance as his initial and continued attitude towards his early death reflected this notion, but also showed that the adoption of a 'stage' is dependent upon the individual's personality (Thompson, Wilson & Mcpherson, 2009); the interest to gather information to aid their understanding of their health (Czaja, Manfredi & Price, 2003; Leydon et al., 2000); their social support (Usta, 2012) as well as the overall situation (Leydon et al., 2000).

5.6.4 Fulfilling Wishes

An intimate experience that Steve shared with audiences was his spontaneous wedding that took place on the ward at the Royal Marsden. After being told that he did not have long to live by his oncologist, he was reminded of one of his wishes, also known as 'unfinished business' (Masterson et al., 2018), that he had previously shared with his doctor, of getting married to his long-time partner. Steve was taking strong opioid-based medication, which can affect a patient's cognitive abilities (Staat & Segatore, 2005). As his liver was shutting down and not processing drugs, the effect of the morphine became more amplified. This meant that he had to be prompted to remember one of his wish fulfilments.

> *For some reason, the palliative care team introduce me to the vicar, the hospital [laughs], the hospital chaplain. I can't, I'm struggling to fathom what this is about anyway. And I you know have talked to (oncologist) about the possible plans to marry in the future…. And (oncologist) says, look if you want to do this marriage thing, I think you should probably do it now… the whole thing was organised within an hour [coughs]*. (S: Int. 19)

The patient-practitioner relationship that Steve and his oncologist shared, entailed good communication and open awareness of his needs and wishes, to the point of his oncologist being aware of his requirements in his personal and social domains of life. This is demonstrative of exceptional and multi-dimensional care (Hanks, Cherny, Christakis, Fallon, Kaasa & Portenoy, 2011), where the care-giver is aware and addresses the various needs of their patient, where possible. The oncologist was able to guide Steve in the timeframe left to live so that his pending wish was not left unfulfilled. Steve went on to share the details of the intimate event and for the second time in the interview series, audiences were invited to share his personal life (the first being his relationship with his sons and on breaking the news of the cancer diagnosis to them).

> S: *The staff amazingly produced a wedding cake, the wife of a gent offered* [wife] *her* [inaudible] *cosmetics. Er the nurses managed to produce erm you know bunched flowers, a wedding cake. Couple of bottles of prosecco appeared from*

goodness knows where and then the ceremony begins. And it was a combination of All Gas and Gaiters.

E*:* [Laughs]

S*: And sort of The Vicar of Dibley really. The idea that Britain doesn't have people in it who really care about other people and will really go the extra mile when it matters is such nonsense. In this little room here, this was Britain at its best you know and it all happened. So, this is probably the quickest and cheapest wedding that has ever been held on the four isles.*

(Int. 19)

After sharing some humour to illustrate the spontaneity of the wedding, the appreciation of the generosity of people was shown, showing the possibility that wishes can be fulfilled at the end-of-life even in hospital care. In a concept analysis of humour in adult cancer, it was found that the use of humour was defined as an emotional response which occurs as a result of comic, absurd or an impulsive situation or actions which enhances feelings of closeness. This also has the potential to act as a coping mechanism or help to relieve tension when dealing with stressful or unfamiliar situations (Tanay, Roberts & Ream, 2013). With the quick organisation of the unplanned wedding, Steve's use of humour to describe the event highlighted the sense of togetherness that he felt on the ward with the input from the nurses, other staff, patients and visitors which had showed the others' sincerity, kindness and consideration at such an important time.

On the other hand, according to Kübler-Ross (1696, p.104), detaching from meaningful relationships makes dying for the individual easier and this is usually the preferred way of 'letting go'. In Steve's case, the opposite of Kübler-Ross's observations was found, in that he made his relationship with his partner official with marriage, creating further attachment as opposed to *detaching*. It is important to consider that Steve's early acceptance and adjustment of the cancer that meant that he did not feel the need to disassociate from his family and that the cancer has instead brought him emotionally closer and open with his family. This was previously highlighted by his sons, *You* [Steve] *now talk about your feelings…. and there's things going on whereas before, that didn't happen. So there's more openness and some transparency with regards to emotions*. (Int. 4). Once again, this process of emotional growth and continued emotional bonds at the end-of-life does not comply with Kübler-Ross's conceptualisation of psychologically and spiritually preparing to die.

This intimate and emotional experience was shared with the audience who had listened to his various interviews which has comprised of his medical, journalistic, psychosocial and now, domestic experiences. This wanting to share these experiences were echoed in his connection felt with the audience, which he fondly reflected upon:

> *The sense of connection that it's created with the audience, I don't think I've felt before. Erm, so that's something that is quite exciting, to feel that you have this kind of relationship with an audience all being about something that's quite difficult erm and that they are genuinely interested in what you've got to say about it… I have to say, it's been a pretty positive experience. My abiding hope is that it's been as positive experience for people who listen to it.* (S: Int. 19)

5.6.5 *A half-way house*

A concept of a 'half-way house' was the preferred environment to spend his last few days at. This emphasised Steve's liking of being in the comfort of his own home with family (5.6.2) with medical needs attended to, rather than going to a hospice. This preference showed that he valued the time and comfort of his domestic life with family and once again, this priority may have guided 'buying time' with treatment and this remained the same till the end stages of his life as seen earlier. However, having learnt of the options and realistic choices that needed to be made in line with the state of his health.

In his last interview with Eddie on the hospital ward, Steve continued to educate the audience about healthcare in cancer, when simply discussing his preference for palliative care options and living arrangements. This last bit of teaching shifted from how to gain the best treatment, to how to sift through the options available at the end-of-life in accordance to one's wishes on where to die in accordance with the help of the palliative care team and the practicality of one's health. As well as this, he deconstructed the types of living arrangements available, highlighting the importance of choice and preparation for a comfortable end-of-life, but still with the essential care required in pain management and dying:

> [Croaky and deep voice]
>
> *It's all very well as we'll go to palliative care, half-way house and so on, but what does that actually mean? You've got to calibrate it somehow. I mean, if my liver is in a bad state as it was a week ago on Friday, er then I don't think there would be any point going to a half-way house. You need to be going somewhere that is probably full on hospice. If on the other hand, the battle if you like, between the rest of the world and my liver and the rest of it improved, then nothing more I'd like more than going home you know, getting set-up in half-way house arrangements. Making sure that all the things are in place you know to make sure that if something were to happen, then it would be in a position to deal with. So, at the moment, we're still in a position where we don't really know where it's at because you could either waste hugely expensive and valuable services in someone who doesn't need them.* (S: Int. 20)

When addressing his future death which could possibly take place at his home (half-way house), Steve used the phrase 'if something were to happen', instead of the words 'death' or 'die'. The continued

outlook of living each day as it came and without allowing his eventual death to be the focus of his time spent relaxing at home with friends. Therefore, not directly using these words helped to lighten the atmosphere as Steve, Eddie and the audience were well aware of the of the next step in Steve's *story*. The removed the focus of death so that he could clearly share the practical and useful information surrounding living arrangements and key ways in which to decipher the correct environment for the individual.

Similar to previous ways of describing medical problems to the audience, Steve made use of warfare imagery (Demmen et al., 2015; Sontag, 1978) to explain that the state of his liver was the main issue preventing his wish to return home to receive hospice care. Although, as previously discussed (5.4.4 & 5.4.5), Steve did not perceive his experience with his cancer and its effects as a 'battle', he usefully adopted this image again for the benefit of his audience's understanding (Casarett et al., 2010) of his end-of-life situation.

5.6.6 A Lasting Impact

Factual reporting was also maintained towards the end of the interview series. Steve continued to prepare notes in order to guide his reporting, which he explained was a useful technique that he has used from his experience as Editor of Panorama. When describing appropriate palliative care settings, Steve was still aware of financial implications and beds availability in UK healthcare. Therefore, when addressing this, he did not allow his personal situation to create a bias perspective when reporting upon settings, even though he as in an unsure position about the health of his liver.

As a result, even when taking strong opioid medication, his professional journalism, educating his audiences, and passion to continue to live was all present at the palliative stage of his life. His declaration to Eddie summed-up exactly this: *But Eddie, it's not over yet mate*. Having left a legacy of scholarships for students to study Media only reinstated the importance of media to Steve of informing people about significant or under-represented stories such as the experience of OC, which ultimately helped to raise awareness. Outcomes of such stories in the media can help patient and family confidence in navigating themselves through cancer treatment and end-of-life decisions. This was echoed by members of the public who called in to share their appreciation and the significant impact that Steve's story had, had upon them:

> *My family were told my mother has advanced bowel cancer last month, we haven't had an oncological appointment yet because we've been awaiting the results of the biopsy, but also we've been battling the serious side effect of the cancer. I think of Steve and his family whenever I travel to the hospital. Whenever I think of my mum, when I'm planning how to get the best care her, or to extract information from NHS doctors. I've listened to each interview several times. Being open and honest about cancer and death as Steve is, diminishes the unknownness and the fear of it. It's lessening my pain that he's made me part of his journey.* (A1: Int. 5)

Steve's reporting was greatly influential in educating and guiding people with family members with cancer, providing almost prescriptive methods of preparing for appointments through sharing detailed information and helping the audience to make sense of the procedures and steps from the cancer diagnosis stage through to the treatment segments of the journey. The fact that an audience member had listened to each of the interviews several times supports this notion of Steve having provided guidance that the audience member found worthwhile. Impact of Steve's reporting was seen in the form of making audiences more knowledgeable, which had the effect of increasing cancer awareness. Therefore, this helped to decrease anxiety and worry of the word 'cancer' and the misconceptions about the illness, done simply through the balance of professional and factual journalism with an intimate and candid commentary of coping with the challenges that arise as someone with cancer.

The impact of Steve's story had a psychosocial effect upon people, particularly those who were going through, or had gone through the journey themselves or with family. Another audience member who had written into the Radio Times Magazine expressed that listening to Steve made him reflect upon his past experiences with healthcare in cancer:

> *I think listening to this has helped me understand that they were trying to protect me from all the scary medical jargon, but listening now, I feel comforted that it doesn't sound as scary as I thought. As odd as it sounds, I think that Steve's conversations about cancer and treatments are helping me to process what happened to my own mother, and I wanted to thank you for this.* (A2: RTM)

Steve's interviews positively triggered personal responses in audiences who then found themselves understanding their past experiences after listening to the interviews, which is something that they had not done at the time of dealing with their or a family member's cancer. This reflection shared by an audience member showed that Steve had helped people who did not necessarily have the educational exposure or openness to cancer at the time. His story provided comfort which supplemented a listener's self-reflection through explaining the cancer diagnosis and treatment process and removing the intimidation that comes with cancer-related language and trying to deconstruct the overwhelming options that are available for treatment. In this case, the information provided by Steve helped the anonymous audience member understand what his mother may have experienced in her treatment with cancer. It is evident that Steve's interviews had impact upon people with all types of experiences with cancer; past and present. This included helping to raise awareness but equally, his conversations created prompts for people to reflect upon some their own experiences.

Another example of the direct impact that the reporting had was conveyed by a member of the public who had written into the Radio Times Magazine in 2017 with their experience with OC.

> *My partner heard your interview in around October time and up until then had dismissed the problems he'd had swallowing. After hearing your interview he went to his GP, endoscopies and biopsies followed, and on 2nd January 2017 he was diagnosed with oesophageal cancer. The cancer has been caught early enough that they can operate on him. He started chemotherapy this week and will be operated on in about 3-4 months' time.*
>
> *He's only 35 and we're told this is an unusual cancer for his age. Every doctor/nurse/consultant we've seen has asked what led him to go to his GP in the first place and every time we say, 'Well, it's all because of Steve Hewlett'….Cancer seems a far less terrifying journey because of your openness. The names of the chemo drugs sound like more familiar terms, and we know the side effects to watch out for. He is now openly sharing his experiences with friends and colleagues in the same way you have with the nation.* (A3: RTM)

Although Steve's cancer was diagnosed late, as mentioned previously, he was able to help others identify potential symptoms through the use of easy to understand explanations (*fizzy pop sensation Int: 1*). Ultimately, he had prepared his audience who may experience cancer in the future, OC in particular, with the knowledge and awareness of dealing with the cancer journey, and to some extent helping to facilitate their confidence in managing their treatment and life through having provided his own personal experiences as teaching examples. Breaking down complex medical procedures, terminology and names of drugs created an impact upon audience in empowering them to have even a basic knowledgebase of treatment and drugs to prevent division between patients and doctors, advocating and allowing for patients to be truly part of their own road to recovery or palliative care.

5.7 Chapter Summary

This chapter incorporates the main and significant events of Steve's journey with OC diagnosis, treatment and end-of-life experience. The transition from an experienced journalist and broadcaster to an expert patient of cancer, uncovered an array of obstacles, pressures and healthcare experiences that aimed to raise awareness on such topics as well as educating and informing the public about the physical, psychological and social effects that cancer can have upon the individual. Sharing these experiences, simultaneously demonstrated ways of accepting and coping with a current situation in order to progress through the journey, gain more time to live and equally try to maintain quality of life. Insider knowledge which derived from being an inquisitive and active patient, was shared with audiences using his professional investigation and reporting skills. His journalistic skills were also used to uncover more knowledge and information about the technical and clinical aspects of the journey, which were supplemented by fact-checking with policies and guidelines. In doing so, Steve aimed to help make sense of the various facets of the journey in the real-life context of his own personal treatment success and failures.

Other key findings of Steve's journey showed his effort to break-down social barriers related to men's health and identity through the example of preventing treatment-related hair-loss and wanting to maintain a sense of self, avoiding the social judgement of a 'victim' of cancer. He diverted from conventionalised speech used to talk about cancer such as warfare metaphor, as this did not capture his real views and experience of his disease; nor did these reflect the reality of his positive coping and adjustment to his bodily changes that he made to manage the effects of the cancer's progression, treatment and side-effects.

However, ways of engaging with the audience through metaphor and humour, made his storytelling of the journey more accessible and relatable, helping to lighten the atmosphere surrounding an intense and intimate topic, creating the balance between his professional and personal reporting. Candid sharing of interactions with family and receiving palliative care, continued to provide an emotionally and intellectually-compelling story until the end of the interview series. Once again, allowing the audience to continue to learn even about the last phase of the cancer journey. These included, preparations for where to die, addressing 'unfinished business' and decision-making surrounding this and, deconstructing expectations of living a fulfilling life and what living a day with the possibility of dying any day is like.

Chapter Six: Conclusion

6.1 Introduction

This concluding chapter presents the key findings and the contribution this thesis makes to knowledge within health reporting in the media using the specific case of Steve Hewlett's commentary on his cancer journey. The contributions made to CS methodology are also explained. Limitations of the study and drawbacks are discussed to provide a sense of the overall usefulness of CS methodology in this specific piece of research. CS propositions are re-examined to identify whether these were met or rejected and there is a re-visit to my personal research outlook and reflexive awareness. Lastly, the chapter concludes with discussions about the implications of cancer and health awareness in the media by journalists or broadcasters, with further recommendations for future research on what can be done to enhance public awareness and understanding of cancer symptoms.

6.2 Key Findings and Novel Contributions to Knowledge

This single CS enabled an in-depth and multi-faceted report upon Steve's journey which covered a range of topics (cancer, health, coping, education, journalism) that were reported through different mediums to interest and engage audiences who followed the journey. The combination of personal and journalism stories about OC showed the multiple ways of Steve's reporting. This included modelling and potentially showing ways to take responsibility for one's own health such as enquiring about delayed referrals; demonstrating shared decision-making process; coping and navigating one's self through the journey using helpful information sources, ultimately exemplifying a way of becoming an informed and expert patient to extend and maintain quality of life where possible by the individual.

These various ways of the Steve's reporting and story-telling were reflected by the various ways that he chose to talk about the different aspects of cancer such as practical aspects: recognising cancer symptoms, how to pursue a specialist referral of treatment, dealing with the physical and emotional side-effects of treatment, discussion of the types of licensed and experimental treatment available and how treatment is monitored, debating the use of language in conceptualising cancer and lastly, understanding the options and care and available at the end of one's life. As a result, Steve's combination of factual and intimate reporting can be likened to a dynamic narrative, which invites the audiences to engage with the experiences or information explained, as opposed to simply providing instructions or imperatives to audiences on seeking help (as seen with NHS 'Be Clear On Cancer' campaigns). Therefore, there could be potential for the impact of increasing public awareness and understanding of vague-to-identify cancers such as OC, through personal reporting by journalists in the media. This would enhance public health communication from limited and simplistic health instructions given by government media campaigns to relatable and contextual information. It is important to note however, that more and in-depth qualitative research is needed to understand

public perceptions on the effectiveness of government-led campaigns compared with other methods such as journalist health stories, which is a now a more common way of raising awareness in the media by media professionals (see future recommendations 6.6).

The exploration of human interest framing (HIF) in health research is vital if we are to raise public awareness of cancer using methods such as journalist reporting of cancer journeys, as seen in Steve's reporting and many other journalists who have followed suit for example, Goeorge Alagiah's podcasts and Bill Turnbull's television documentary (1.2.1). Steve's story demonstrated the type of information that could be reported on, in the media, to potentially help and educate audiences, and was especially useful in relation to a cancer with vague symptoms, such as OC. Furthermore, this CS adds to the concept of HIF by providing guidance on the types of topics that can be covered in cancer reports and the ways in which these can be framed to achieve real impact within the context of cancer. For example, Steve's reporting shed light on the importance of in-depth coverage of a multitude of topics encountered in cancer and care as a patient. This included technical aspects, such as dealing with pain or treatment side-effects and psychosocial aspects, such as experiencing acceptance of an early death and coping with and making-sense of obstacles to life-extending treatment.

This case uncovers that journalists reporting cancer experiences can provide ways of modelling thoughts (thinking about how to approach a sensitive situation, critically questioning decisions made by health professionals on one's behalf, questioning new symptoms) and behaviour (seeking help, liaising with healthcare staff, communicating during unsure or challenging times, involving one's-self in health decisions). This type of self-reporting can help audiences to better understand the health information being shared with them, how they can learn from it and how they can implement it. Ultimately, HIF may be able to help people to navigate themselves through a cancer journey. This was evidenced by Steve's audience members who were either diagnosed with cancer themself or had family members diagnosed with cancer. However, as stated, more research is required to support these notions.

The CS also addresses the issue of journalists' perceptions that they must rely on appealing to audience's emotions to engage them in cancer stories using HIF (Hinnant et al., 2013). This was done by demonstrating that a fluid and balanced story can be achieved which allows for sharing of factual information and the lived experience and thoughts through a journalist's trustworthy and effective narrative. In addition, this study shows that HIF in health awareness reporting is most effective when the story is reported for an extended amount of time, as done by Steve. In doing so, the reporter has the time and opportunity to share the various aspects of their life and demonstrate the changes and challenges that arise during something like a cancer journey, helping to provide a better understanding of dealing with cancer at each stage of the journey and overall.

As stated by Kreuter et al. (2007), narratives about a person's illness in media reporting can lead to inaccurate information as stories can be subjective and unreliable. However, this thesis demonstrates that HIF employed by journalists themselves, to voluntarily share their personal health stories, has the potential to be influential. This was seen when Steve supplemented his experiences with facts, policy and questioning of his cancer care and standard care practice, which was of course facilitated by Eddie Mair, a very skilled journalist who expertly guided the interviews. Moreover, their ability to use their own journalistic skills and apply these seamlessly to their encounters with illness treatment, health staff, hospital stays and domestic affairs such as family and finances allows for a comprehensive holistic understanding of the illness and its effects relevant and enlightening to the public and health professionals alike. Steve's story, therefore is a strong example of why journalist's stories should be valued, in the effort to raise public cancer awareness, and why more journalists reporting on their own stories is beneficial to the public health.

Intertextuality was inescapable and present throughout most parts of Steve's interviews, particularly as references were made to existing 'cancer talk' and conceptual situations of those with cancer. It was an ongoing mechanism used to develop and challenge existing ways in which cancer is spoken about and how those with cancer are referred to ('fighters', 'victims') As discussed within the findings, the adoption of conventional imagery such an *enemy* and *battle* was refused by Steve but these were still discussed in order to address normalised speech that he felt did not reflect his perceptions or experience as a person with cancer. Steve's openness and dedicated interviews about his cancer treatment and the cancer healthcare pathway, was also adopted by other journalists afterwards. This was seen with BBC journalist George Alagiah's podcasts in association with Bowel Cancer UK, with medical professionals and invited guests diagnosed with cancer. Within George's podcasts, he took on the role of host as someone with cancer themselves, experienced with the cancer pathway and as an individual who had been diagnosed twice in the past few years (2014 and then again in 2017). Before 2020, George had not reported on his cancer in depth. These podcasts are reminiscent of the topics discussed in Steve's interviews and diary entries (chemotherapy, emotional health, family and cancer), from which it is evident that George had developed upon the reporting style of a journalist with cancer by sharing information directly from expert guests to educate and uncover the obstacles faced by those with bowel cancer. This CS could act as a basis for other journalists wanting to share their experiences by demonstrating the type of content that could be discussed and the style in which it could be communicated to audiences. As seen in George's podcast, influence taken from previous cancer narratives, such as Steve's, shows methods of storytelling and how this can be adopted for a different type of cancer and information specific to it.

Overall, intertextuality can be seen to play a part in progressing previous and existing speech or text and, has the potential to weave influential aspects from one context to another (e.g. interviews surrounding oesophageal cancer journey to podcasts about living with bowel cancer). This is a useful tool of speech or writing that can facilitate journalists' ways of making dialogue surrounding coping and living with cancer more relevant to the changing perceptions of health, with the potential of increasing patient health literacy (Dentzer, 2009; Metzl, Caplan & Wahl, 2004) and potentially patient responsibility for their own health but further research is required to understand this more.

6.2.1 Contribution to Methodology

This study provides a strong example of the use of a single CS and its impact in the context of raising awareness through the story of a journalist-patient within the media, which has not yet been conducted in this capacity within social research. This study is also the first of its kind and with a focus upon OC in particular, and its related care experiences studied in an in-depth CS about the journey of a journalist and their health.

This thesis re-enforces that a single CS based on the experiences of one person can have substantial and positive implications for the society and public health. The findings of the research support Flyvbjerg's (2006) proposed misunderstanding that a single CS cannot generate transferable findings or conclusions due to the quantity of research produced. As a result, it is also misconceived that a single CS cannot contribute to social scientific development. The current CS has evidenced the scope and transferability of a single CS, which is based on the growing phenomenon of journalists and broadcasters reporting upon their own health and overstepping their personal boundaries for the holistic reporting of cancer. As this is something that is now becoming a more frequent occurrence within the media and storytelling (as seen by latest examples with Jeremey Bowen and Bill Turnbull), this CS on Steve Hewlett's reporting and experiences helps to demonstrate the impact that a journalist can have on public health. Furthermore, this thesis has helped to highlight the health communication and journalistic techniques that are used to connect to and engage audiences to help them understand the many aspects of cancer. This thesis can therefore be referred to, to identify useful topics that can covered by journalists should they wish to share their personal health journey and to also understand the helpful ways that journalists can impact cancer awareness with their access to media.

Another contribution pertains to the use of hermeneutics within this CS thesis, where pre-existent data has been used. This thesis shows that hermeneutics, used in this way, can gain a balanced level of interpretivism, which is not so deeply analysed as to lose a person's originally-intended meaning of the experiences shared (Husserl circa 1970, see Husserl, 2012). Hermeneutics, therefore allows for an overall and general level of interpretation without the motive of uncovering essences of experiences, or perceptions or constructions of events, which is a useful concept when a researcher cannot use

member checking to confirm validity of their interpretations or clarify data further. With more upcoming journalist reports and storytelling of cancer, psychosocial and communication research may wish to consider employing a hermeneutical stance in order to access a credible amount of understanding when interpreting data that can no longer be confirmed (member-checked) by a living journalist or broadcaster.

6.3 Case Propositions

The case propositions guided the analysis of the CS to explore whether Steve's reasons and interests to share his cancer journey was guided by the points highlighted earlier (3.2.7). These propositions were,

- Steve Hewlett was influenced by his journalistic background to explore and share his journey of cancer;
- he shared his journey for the benefit of audiences;
- having a media platform facilitated the sharing of information;
- the sharing of experiences was also dependent upon his physical health but not due to successful or unsuccessful treatment.

The findings demonstrated most predictions were correct and that Steve was influenced by his journalistic background and took advantage of his access to a media platform to raise awareness of OC, irrespective of successful or unsuccessful treatment, as outcomes of this did not deter his willingness to share his story and educate the audience. However, the last proposition was contested as even though Steve's voice deteriorated, and he was experiencing the strong side-effects of morphine during the end stages of his life, he was still able to give his last interview clearly before passing away. This was a powerful interview in itself as Steve had officially been given *notice* of dying (5.4.5), yet he still made time and effort to record this interview with Eddie while sat on a hospital bed. In effect, this demonstrates the proposition that he was adamant to share his story, irrespective of a 'good' or 'bad' ending as his flair for journalism and storytelling were the driving forces behind raising awareness about OC.

6.4 Reflexivity

When I reflect upon my background within healthcare and health psychology, I have developed a more in-depth understanding of the overlap between different social, psychological and medical areas that can arise when studying a person's cancer experiences. These specific areas include, health communication, coping strategies, medical and clinical concepts (health policy, diagnosis, cancer treatment) and, socialisation of language which is used in healthcare to describe cancer. My

understanding was further developed due to studying these areas that arose due to the use of journalism by Steve to uncover and report the various aspects of his journey.

Producing this CS has also aided my understanding of the interplay and overlap between the different areas in cancer care and experiences that I have not had the chance to explore in previous research. I found that analysing a vast amount of data that entailed aspects from various disciplines (social, psychological, medical) did not have a clear direction for the findings overall, which was due to the various topics reported on (personally and professionally). However, this only reflected the wide scope that interviews within the media can achieve, such as a raising awareness, educating the public, promoting media advocacy and challenging stigma as well as conventionalised ways of addressing the existence of cancer. Therefore, this thesis encouraged me to draw upon the different disciplines that I do not have formal training in, to be able to understand examples and that conceptually addressed Steve's diverse experiences.

6.5 Limitations of The Study

A main limitation in this CS is that I was unable to confirm my interpretation of events and motives to share certain information with Steve himself, to ensure the validity of the analysis. I have used triangulation techniques to ensure validity of findings, however confirming and member-checking details directly with the person whose journey has been analysed ensures that analysis is tied to the text of the interviews, but it may also have significantly enhanced the level of validity. On the other hand, this perceived limitation is also an inherent strength of the study, as the analysis of the data used was purely based upon the pre-existing data available on the internet and podcast archives. This is the same information that was and is continued to be available to audiences. Therefore, not member-checking has meant that analysis and implications drawn from Steve's journey have been reflective of the reality of what was reported and how this was portrayed and received by audiences. This was irrespective of Steve's original, personal and unshared intentions as a reporter of his own cancer.

Another limitation is that the research did not include multiple case studies which would be useful to compare and contrast methods of reporting and storytelling about cancer as done by other journalists. This could then provide more insights into the types of techniques used by journalists in general when raising awareness for certain types of cancer. This is an area that would benefit from more research in the future. It is important to mention that this was not done in this CS as it was extensive in nature due to the story having been reported over a prolonged period of time, providing a vast amount of data to analyse to allow for sufficient conclusions about cancer awareness through the use of journalism. Hence, Steve's in-depth journey and diverse reporting warranted a single CS.

Thirdly, a limitation to consider is that I did not address the differences that can occur in written and spoken data (verbal interview and a written diary entry). This would have been a useful exploration when analysing the data contextually to allow any recognition of variations in the way that experiences or topics were discussed live or asynchronously by Steve. During the extensive analysis of the collated data (80,000 words), I found that although the general content addressed by Steve was identical in both his PM interviews with Eddie Mair and within his diary entries, it may be worth analysing non-lexical or contextual aspects of these types of data that could explore the differences in reporting within the different mediums of the media. This is an area that I will look to explore in further qualitative studies, comparing recent journalist cancer stories for their communication and style of reporting used to create dialogue about cancer or raise awareness of this among their audiences.

Lastly, the study would have benefitted from further exploration of audience or public views, and the impact that they felt (if any) from Steve's reporting. These would most likely be from an audience of middle class who are likely to be older (listeners and readers of BBC Radio 4 and Radio Times). A few public declarations (phone calls to the PM show and letters written to the Radio Times magazine) were analysed which demonstrated the effect of Steve's reporting upon their own or a family's health. However, directly interviewing more members of the public who followed Steve's journey, would provide even more insight into just how influential this method of raising cancer awareness can be. This would also create another way of triangulating the findings of the CS on a larger scale; helping to increase the validity of this type of novel single CS.

In reference to methodological considerations, a potential limitation is that as the data was pre-existing, the setting of case boundaries was done after all data was collated and assessed for relevance, which does not reflect truly inductively-collected data. Being able to set boundaries post data collation is useful when dealing with a vast amount of data, however, this could also mean that the researcher may unknowingly or sub-consciously be selective in the data included for analysis such that some data may be omitted if these do not comply with the researcher's personal biases or set research question.

6.6 Possible Implications for Future Health Awareness and Future Research

This CS shows indicates the need for further research so that the effects of cancer story-telling up on audiences can be understood. As showed in the limited audience testimonies within this CS, there may be potential to engage audiences through the use of journalistic and communicative techniques (narrative and metaphor) to provide information about cancer. As a result, this may possibly create a range of positive implications for the benefit of public health. Promoting earlier symptom recognition by improving health awareness by educating the public about warning signs and symptoms, is more effective than screening for cancer (Gøtzsche & Jørgensen, 2013). Therefore, it may be useful for

research to look at the effectiveness of creative and interactional methods of providing information for public health concerns. This is where the use of cancer storytelling in journalism could be explored in relation to the audience and how health campaigns could make use of these types of ways of bringing information to the public.

The uncovering of personal challenges that arise in coping with cancer, and the efforts and struggle of gaining more time to live, along with exposing the sometimes harsh reality of living with cancer in an informative and journalistic manner, could have the potential help normalise conversation about the illness, palliative care and death, which is something that we see Steve try to do when discussing his own ideas and options surrounding death (5.6). Frank (1998) and Williams (2011) echo that storytelling can have positive effects upon others, helping them in the healing and adjustment process of their own illness. LeShan (1989) also proposed that sharing difficult experiences about cancer, with each other can help alleviate the stress that comes with a cancer diagnosis, to help with the transition towards post-traumatic growth. As 'growth' can mean reducing one's fear of the disease, exposing the types of cancer experiences may help to no longer leave this as unknown or mysterious to those who have no previous knowledge or experience of dealing with cancer.

Should research demonstrate that audiences can benefit from journalist storytelling about cancer, it would be beneficial for public health bodies to consider backing these types of information-sharing and engaging accounts, to not only improve health literacy where applicable, but to also promote personal health responsibility in the cancer journey. Ultimately, there is potential to then facilitate empowerment in cancer and at the end stages of life through demonstration and explanation by those in the media. This also supports a recommendation made by Wakefield et al. (2018, p.1288), "Greater efforts should be made to progress the empowerment of patients nearing the end of their lives." In effect, the promotion of self-empowerment through gaining more knowledge about the cancer experience, medical processes and types of treatment options (where relevant) may then be integrated into journalist storytelling. This could include modelling ways to be involved in one's own health at any stage of the cancer (or end-of-life) journey, but also shedding light for health professionals and family members who can learn and gain ideas about ways to facilitate empowerment and to support those with cancer. However, without further research following on from this CS, journalist stories cannot be meaningfully used to help audiences with their health in this capacity.

To reiterate, as mentioned within section 4.2.1, shallow analysis of these audience comments were speculative due to the limited testimonies and data available. Further investigation of public views and testimonies about how they have been affected by journalist cancer stories, would be a worthwhile study within the cancer-journalism narrative, because in being able to clearly understand

if and how these types of journalist stories influence audiences, would then allow academics to demonstrate the true effects of the efforts made by journalists and how certain communication methods used by journalists can be standardised, or taken influence from for future public health initiatives in raising awareness about cancer. To emphasise, this CS can, as a result of briefly drawing upon these audience testaments, act as a catalyst to a number of useful areas of research in cancer and journalism, that can be conducted to understand the long-term implications of the personal narrative by a journalist upon public health, public education and potentially, personal responsibility of health. However, in order to do this, multiple journalist stories should be qualitatively-analysed, supported by multiple audience testaments to progress our understanding of the real impact of cancer reporting in the media.

Other research should encompass multiple case studies and evaluation of their impact upon audiences. Other techniques used to inform, educate and empower audience in cancer could then be built upon, from the current single CS research to demonstrate useful techniques that can act as standardised methods to use in cancer reporting in the media for optimum impact upon audiences.

6.7 Dissemination of Findings

In order to share the findings of this research, there are planned conference attendances and research papers to facilitate this. This includes the Medical Sociology Conference and the Division of Health Psychology Conference. Papers that I plan to publish include a succinct version of Steve's cancer journey using CS methodology to demonstrate the usefulness of case studies in the context of health, media and journalism. Another paper will focus on providing guidance on the use of HIF for journalists wanting to report their own cancer experiences in the media, using examples Steve's techniques for raising cancer awareness. I also aim to publish about the use of health awareness language, communication techniques and ways of empowering oneself during treatment phases and also at the end-of-life in palliative and hospice care, as evidence by this study. I will therefore revisit LOROS, Leicester (hospice) to provide an update upon the usefulness of media and cancer awareness and patient involvement in self-empowerment at the end-of-life care. This may help to act as a reference point for nurses, oncologists and registrars to refer patients to relevant stories in the media, should they wish to know more about the type of expected experiences and coping at the end stages of cancer.

In addition, I will aim to reach out to national media, such as Radio Four and Radio Times to inform about them of the CS into Steve's journey and the findings that I have concluded from his valuable contribution to raising cancer awareness through journalism and storytelling.

6.8 Conclusion

The purpose of this thesis was to make an original and novel contribution to the understanding of how a journalist's story of cancer used various and creative techniques to raise awareness about the cancer journey (from diagnosis to the end stages of life) within OC. These included metaphors, frames and health narratives that may be available to audiences when interacting with journalist cancer stories to make sense of certain cancer experiences and the healthcare system. The combination of personal and journalistic reporting about OC showed the multiple methods of Steve's reporting. This included modelling and potentially showing ways to take responsibility for one's own health such as enquiring about delayed referrals; demonstrating shared decision-making process; coping and navigating one's self through the journey using helpful information sources, ultimately exemplifying a way of becoming an informed and potentially 'expert' patient.

It is equally important to note that this CS is a modest exploratory study which requires further triangulation with audience views so that these can be explored in depth so that these can provide a truer reflection of the impact that Steve's story had upon the public's health knowledge and their experience of dealing with suspected cancer or the cancer journey itself. However, this study provides the foundation required to be able to investigate audience perceptions of journalist storytelling, by providing in-depth analysis of Steve's detailed and extensively reported cancer journey, which is something that has not been done so far for a single journalist story, to date.

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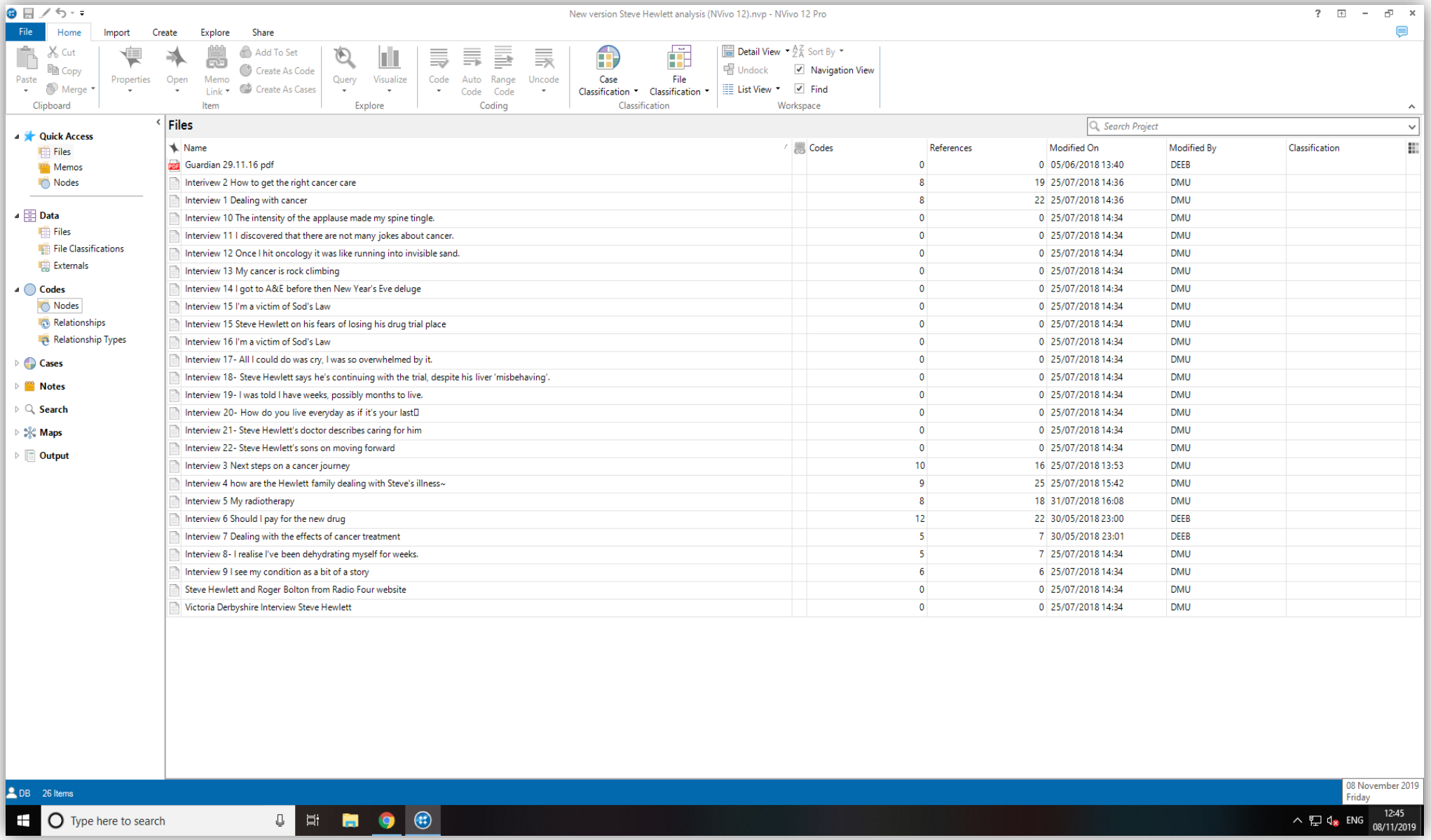
Appendices

Appendix 1


New version Steve Hewlett analysis (NVivo 12).nvp - NVivo 12 Pro
File
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Visualize
Explore
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Auto Code
Range Code
Uncode
Coding
Case Classification
File Classification
Classification
Detail View
Sort By
Undock
Navigation View
List View
Find
Workspace
Quick Access
Files
Memos
Nodes
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File Classifications
Externals
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Relationship Types
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Interview 1 Dealing with cancer 8 22 25/07/2018 14:36 DMU
Interview 10 The intensity of the applause made my spine tingle. 0 0 25/07/2018 14:34 DMU
Interview 11 I discovered that there are not many jokes about cancer. 0 0 25/07/2018 14:34 DMU
Interview 12 Once I hit oncology it was like running into invisible sand. 0 0 25/07/2018 14:34 DMU
Interview 13 My cancer is rock climbing 0 0 25/07/2018 14:34 DMU
Interview 14 I got to A&E before then New Year's Eve deluge 0 0 25/07/2018 14:34 DMU
Interview 15 I'm a victim of Sod's Law 0 0 25/07/2018 14:34 DMU
Interview 15 Steve Hewlett on his fears of losing his drug trial place 0 0 25/07/2018 14:34 DMU
Interview 16 I'm a victim of Sod's Law 0 0 25/07/2018 14:34 DMU
Interview 17- All I could do was cry, I was so overwhelmed by it. 0 0 25/07/2018 14:34 DMU
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Interview 19- I was told I have weeks, possibly months to live. 0 0 25/07/2018 14:34 DMU
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Interview 22- Steve Hewlett's sons on moving forward 0 0 25/07/2018 14:34 DMU
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Interview 4 how are the Hewlett family dealing with Steve's illness~ 9 25 25/07/2018 15:42 DMU
Interview 5 My radiotherapy 8 18 31/07/2018 16:08 DMU
Interview 6 Should I pay for the new drug 12 22 30/05/2018 23:00 DEEB
Interview 7 Dealing with the effects of cancer treatment 5 7 30/05/2018 23:01 DEEB
Interview 8- I realise I've been dehydrating myself for weeks. 5 7 25/07/2018 14:34 DMU
Interview 9 I see my condition as a bit of a story 6 6 25/07/2018 14:34 DMU
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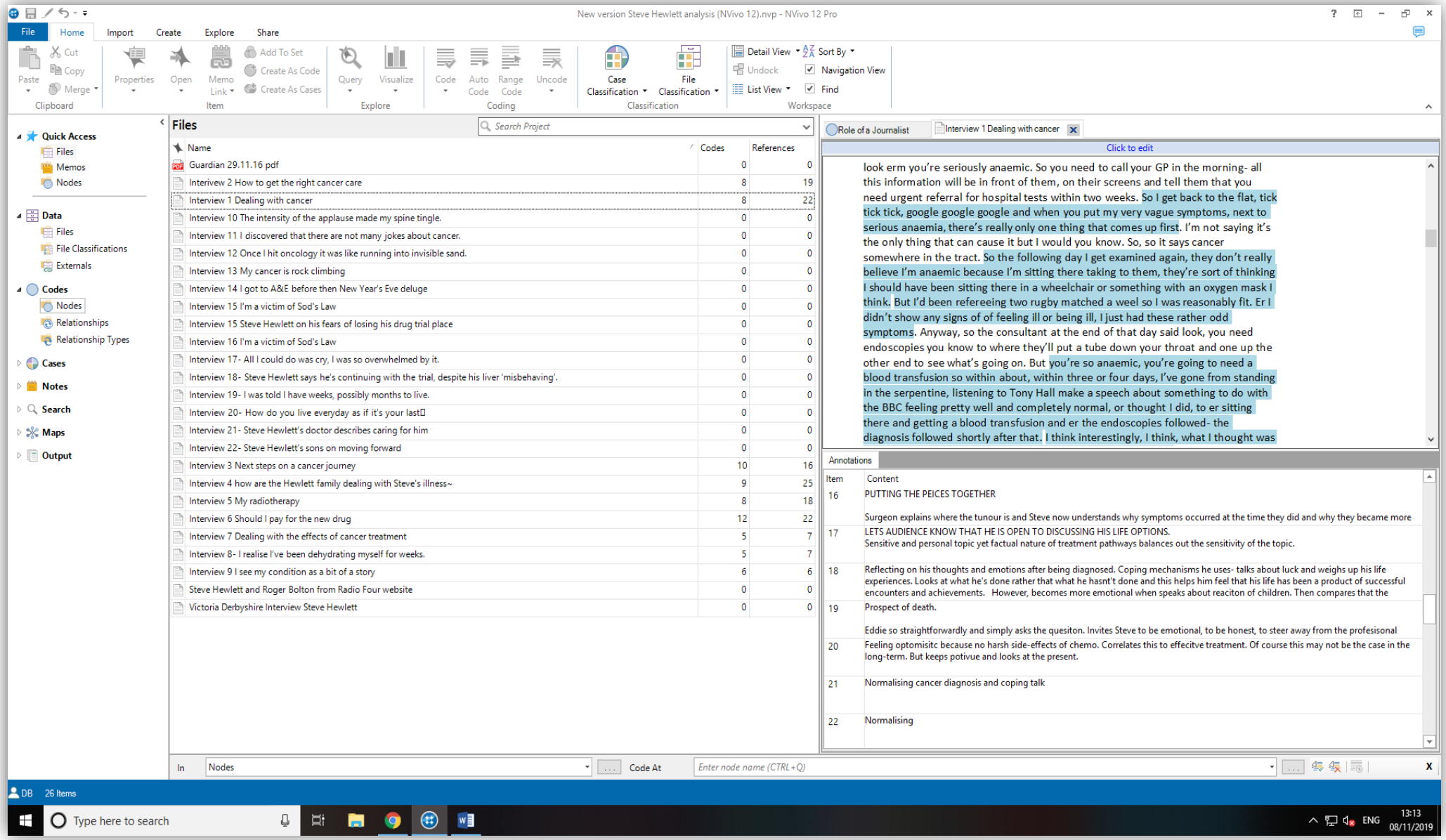
Appendix 2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Guardian 29.11.16 pdf
Interivew 2 How to get the right cancer care
Interview 1 Dealing with cancer
Interview 10 The intensity of the applause made my spine tingle.
Interview 11 I discovered that there are not many jokes about cancer.
Interview 12 Once I hit oncology it was like running into invisible sand.
Interview 13 My cancer is rock climbing
Interview 14 I got to A&E before then New Year's Eve deluge
Interview 15 I'm a victim of Sod's Law
Interview 15 Steve Hewlett on his fears of losing his drug trial place
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Interview 17- All I could do was cry, I was so overwhelmed by it.
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Interview 19- I was told I have weeks, possibly months to live.
Interview 20- How do you live everyday as if it's your last
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Interview 8- I realise I've been dehydrating myself for weeks.
Interview 9 I see my condition as a bit of a story
Steve Hewlett and Roger Bolton from Radio Four website
Victoria Derbyshire Interview Steve Hewlett
Role of a Journalist
Interview 1 Dealing with cancer
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look erm you're seriously anaemic. So you need to call your GP in the morning- all this information will be in front of them, on their screens and tell them that you need urgent referral for hospital tests within two weeks. So I get back to the flat, tick tick tick, google google google and when you put my very vague symptoms, next to serious anaemia, there's really only one thing that comes up first. I'm not saying it's the only thing that can cause it but I would you know. So, so it says cancer somewhere in the tract. So the following day I get examined again, they don't really believe I'm anaemic because I'm sitting there taking to them, they're sort of thinking I should have been sitting there in a wheelchair or something with an oxygen mask I think. But I'd been refereeing two rugby matched a weel so I was reasonably fit. Er I didn't show any signs of of feeling ill or being ill, I just had these rather odd symptoms. Anyway, so the consultant at the end of that day said look, you need endoscopies you know to where they'll put a tube down your throat and one up the other end to see what's going on. But you're so anaemic, you're going to need a blood transfusion so within about, within three or four days, I've gone from standing in the serpentine, listening to Tony Hall make a speech about something to do with the BBC feeling pretty well and completely normal, or thought I did, to er sitting there and getting a blood transfusion and er the endoscopies followed- the diagnosis followed shortly after that. I think interestingly, I think, what I thought was
Annotations
Item
Content
16
PUTTING THE PEICES TOGETHER
Surgeon explains where the tunour is and Steve now understands why symptoms occurred at the time they did and why they became more
17
LETS AUDIENCE KNOW THAT HE IS OPEN TO DISCUSSING HIS LIFE OPTIONS.
Sensitive and personal topic yet factual nature of treatment pathways balances out the sensitivity of the topic.
18
Reflecting on his thoughts and emotions after being diagnosed. Coping mechanisms he uses- talks about luck and weighs up his life experiences. Looks at what he's done rather that what he hasn't done and this helps him feel that his life has been a product of successful encounters and achievements. However, becomes more emotional when speaks about reaciton of children. Then compares that the
19
Prospect of death.
Eddie so straightforwardly and simply asks the quesiton. Invites Steve to be emotional, to be honest, to steer away from the profesisonal
20
Feeling optomisitc because no harsh side-effects of chemo. Correlates this to effecitve treatment. Of course this may not be the case in the long-term. But keeps potivue and looks at the present.
21
Normalising cancer diagnosis and coping talk
22
Normalising
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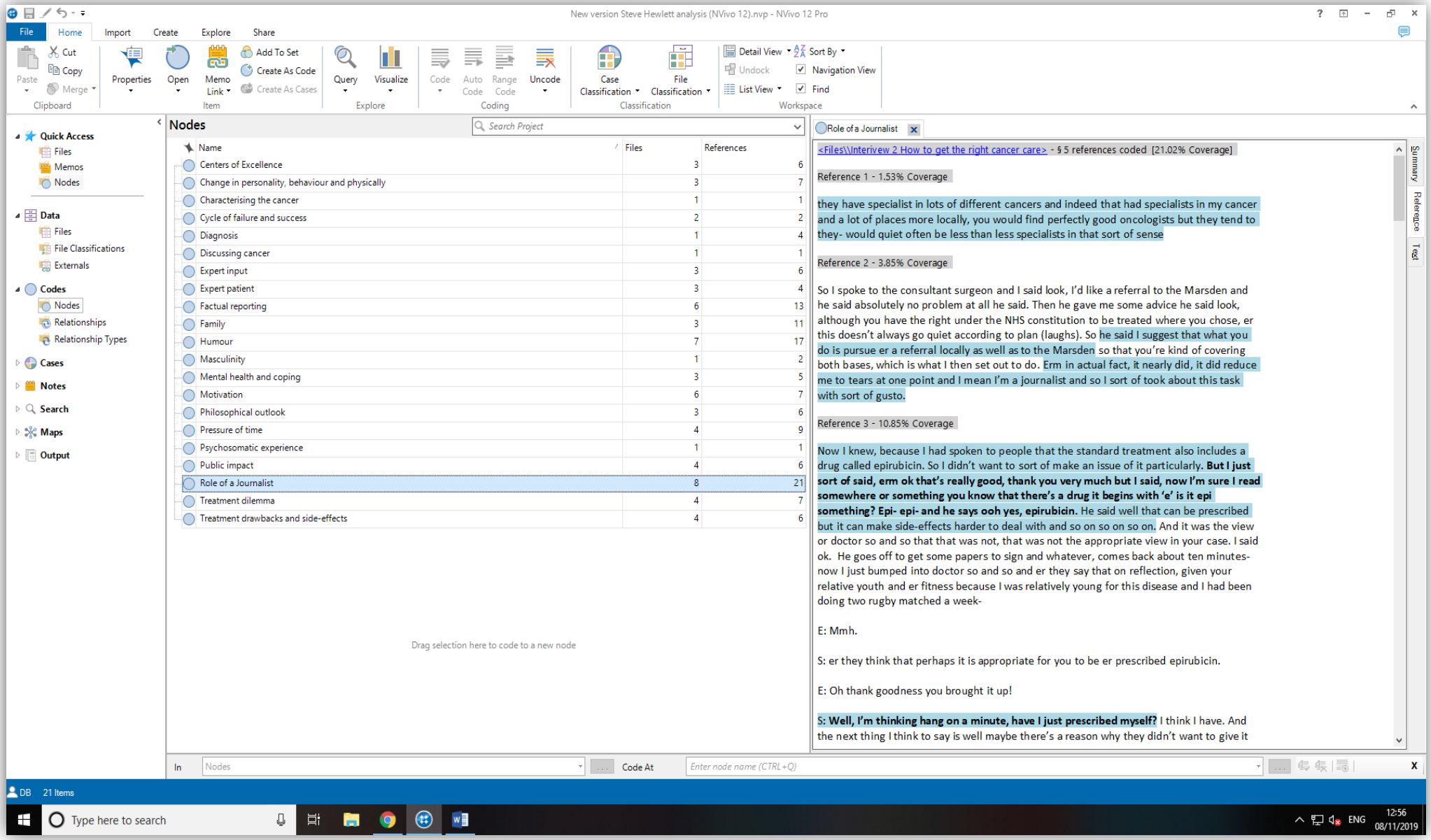
Appendix 3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Change in personality, behaviour and physically 3 7
Characterising the cancer 1 1
Cycle of failure and success 2 2
Diagnosis 1 4
Discussing cancer 1 1
Expert input 3 6
Expert patient 3 4
Factual reporting 6 13
Family 3 11
Humour 7 17
Masculinity 1 2
Mental health and coping 3 5
Motivation 6 7
Philosophical outlook 3 6
Pressure of time 4 9
Psychosomatic experience 1 1
Public impact 4 6
Role of a Journalist 8 21
Treatment dilemma 4 7
Treatment drawbacks and side-effects 4 6
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Role of a Journalist
<Files\\Interivew 2 How to get the right cancer care> - § 5 references coded [21.02% Coverage]
Reference 1 - 1.53% Coverage
they have specialist in lots of different cancers and indeed that had specialists in my cancer and a lot of places more locally, you would find perfectly good oncologists but they tend to they- would quiet often be less than less specialists in that sort of sense
Reference 2 - 3.85% Coverage
So I spoke to the consultant surgeon and I said look, I'd like a referral to the Marsden and he said absolutely no problem at all he said. Then he gave me some advice he said look, although you have the right under the NHS constitution to be treated where you chose, er this doesn't always go quiet according to plan (laughs). So he said I suggest that what you do is pursue er a referral locally as well as to the Marsden so that you're kind of covering both bases, which is what I then set out to do. Erm in actual fact, it nearly did, it did reduce me to tears at one point and I mean I'm a journalist and so I sort of took about this task with sort of gusto.
Reference 3 - 10.85% Coverage
Now I knew, because I had spoken to people that the standard treatment also includes a drug called epirubicin. So I didn't want to sort of make an issue of it particularly. But I just sort of said, erm ok that's really good, thank you very much but I said, now I'm sure I read somewhere or something you know that there's a drug it begins with 'e' is it epi something? Epi- epi- and he says ooh yes, epirubicin. He said well that can be prescribed but it can make side-effects harder to deal with and so on so on so on. And it was the view or doctor so and so that that was not, that was not the appropriate view in your case. I said ok. He goes off to get some papers to sign and whatever, comes back about ten minutes- now I just bumped into doctor so and so and er they say that on reflection, given your relative youth and er fitness because I was relatively young for this disease and I had been doing two rugby matched a week-
E: Mmh.
S: er they think that perhaps it is appropriate for you to be er prescribed epirubicin.
E: Oh thank goodness you brought it up!
S: Well, I'm thinking hang on a minute, have I just prescribed myself? I think I have. And the next thing I think to say is well maybe there's a reason why they didn't want to give it
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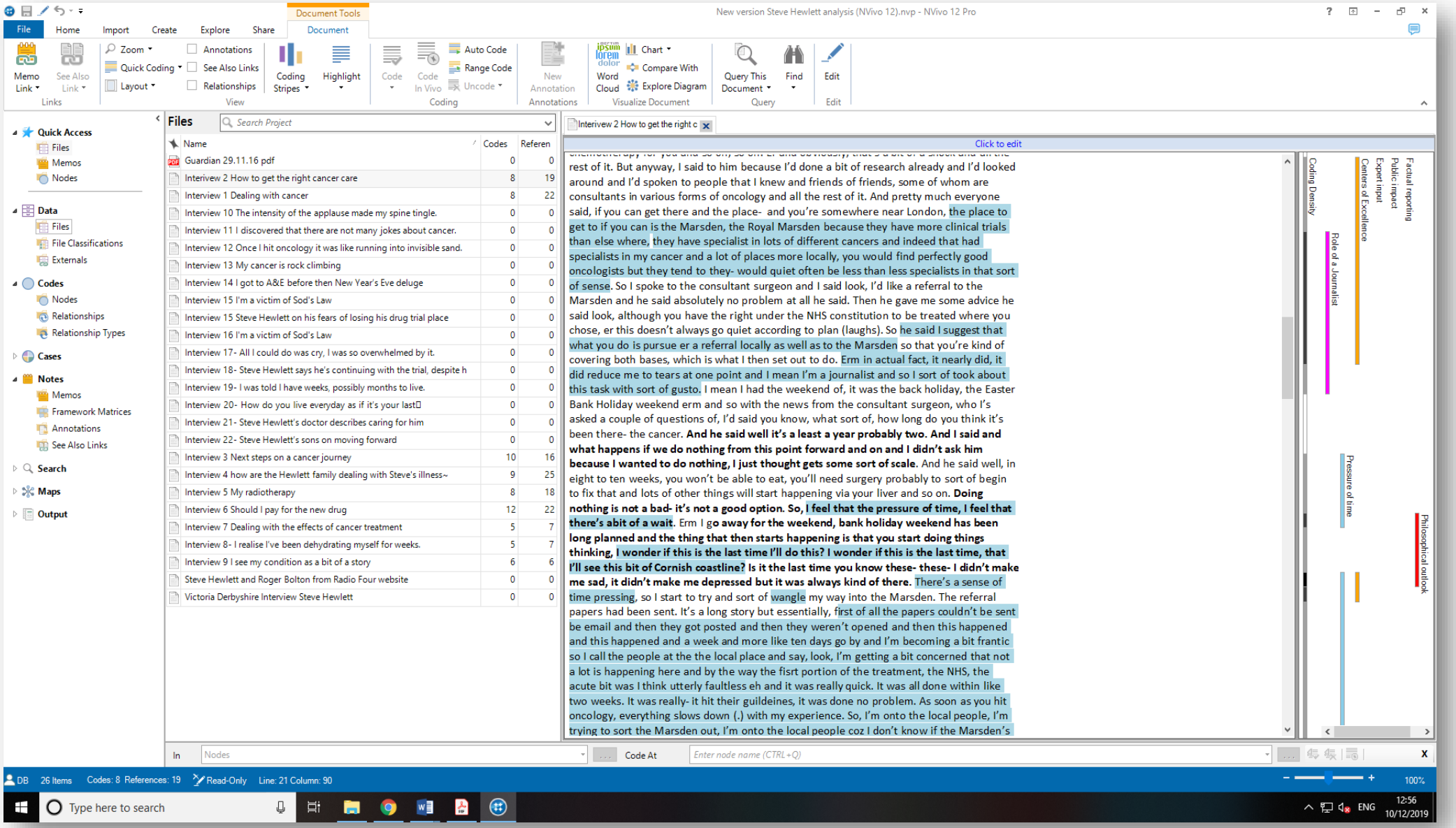
Appendix 4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Interview 13 My cancer is rock climbing 0 0
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Interview 15 Steve Hewlett on his fears of losing his drug trial place 0 0
Interview 16 I'm a victim of Sod's Law 0 0
Interview 17- All I could do was cry, I was so overwhelmed by it. 0 0
Interview 18- Steve Hewlett says he's continuing with the trial, despite h 0 0
Interview 19- I was told I have weeks, possibly months to live. 0 0
Interview 20- How do you live everyday as if it's your last 0 0
Interview 21- Steve Hewlett's doctor describes caring for him 0 0
Interview 22- Steve Hewlett's sons on moving forward 0 0
Interview 3 Next steps on a cancer journey 10 16
Interview 4 how are the Hewlett family dealing with Steve's illness~ 9 25
Interview 5 My radiotherapy 8 18
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Interview 8- I realise I've been dehydrating myself for weeks. 5 7
Interview 9 I see my condition as a bit of a story 6 6
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Victoria Derbyshire Interview Steve Hewlett 0 0
Interivew 2 How to get the right c
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rest of it. But anyway, I said to him because I'd done a bit of research already and I'd looked around and I'd spoken to people that I knew and friends of friends, some of whom are consultants in various forms of oncology and all the rest of it. And pretty much everyone said, if you can get there and the place- and you're somewhere near London, the place to get to if you can is the Marsden, the Royal Marsden because they have more clinical trials than else where, they have specialist in lots of different cancers and indeed that had specialists in my cancer and a lot of places more locally, you would find perfectly good oncologists but they tend to they- would quiet often be less than less specialists in that sort of sense. So I spoke to the consultant surgeon and I said look, I'd like a referral to the Marsden and he said absolutely no problem at all he said. Then he gave me some advice he said look, although you have the right under the NHS constitution to be treated where you chose, er this doesn't always go quiet according to plan (laughs). So he said I suggest that what you do is pursue er a referral locally as well as to the Marsden so that you're kind of covering both bases, which is what I then set out to do. Erm in actual fact, it nearly did, it did reduce me to tears at one point and I mean I'm a journalist and so I sort of took about this task with sort of gusto. I mean I had the weekend of, it was the back holiday, the Easter Bank Holiday weekend erm and so with the news from the consultant surgeon, who I's asked a couple of questions of, I'd said you know, what sort of, how long do you think it's been there- the cancer. **And he said well it's a least a year probably two. And I said and what happens if we do nothing from this point forward and on and I didn't ask him because I wanted to do nothing, I just thought gets some sort of scale.** And he said well, in eight to ten weeks, you won't be able to eat, you'll need surgery probably to sort of begin to fix that and lots of other things will start happening via your liver and so on. **Doing nothing is not a bad- it's not a good option. So, I feel that the pressure of time, I feel that there's abit of a wait.** Erm I go **away for the weekend, bank holiday weekend has been long planned and the thing that then starts happening is that you start doing things thinking, I wonder if this is the last time I'll do this? I wonder if this is the last time, that I'll see this bit of Cornish coastline? Is it the last time you know these- these- I didn't make me sad, it didn't make me depressed but it was always kind of there.** There's a sense of time pressing, so I start to try and sort of wangle my way into the Marsden. The referral papers had been sent. It's a long story but essentially, first of all the papers couldn't be sent be email and then they got posted and then they weren't opened and then this happened and this happened and a week and more like ten days go by and I'm becoming a bit frantic so I call the people at the the local place and say, look, I'm getting a bit concerned that not a lot is happening here and by the way the fisrt portion of the treatment, the NHS, the acute bit was I think utterly faultless eh and it was really quick. It was all done within like two weeks. It was really- it hit their guildeines, it was done no problem. As soon as you hit oncology, everything slows down (.) with my experience. So, I'm onto the local people, I'm trying to sort the Marsden out, I'm onto the local people coz I don't know if the Marsden's
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Public impact
Expert input
Centers of Excellence
Role of a Journalist
Pressure of time
Philosophical outlook
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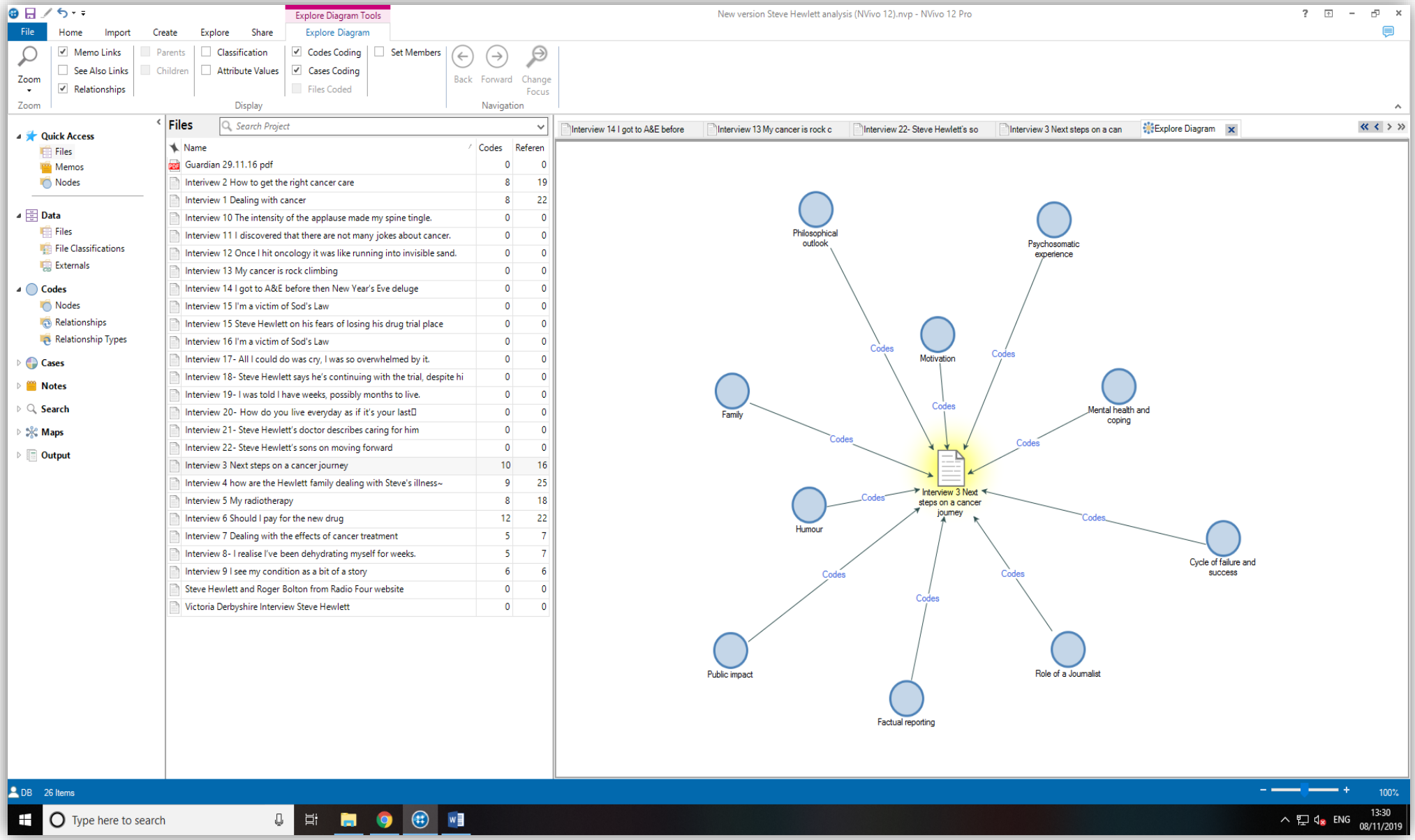
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Role of a Journalist
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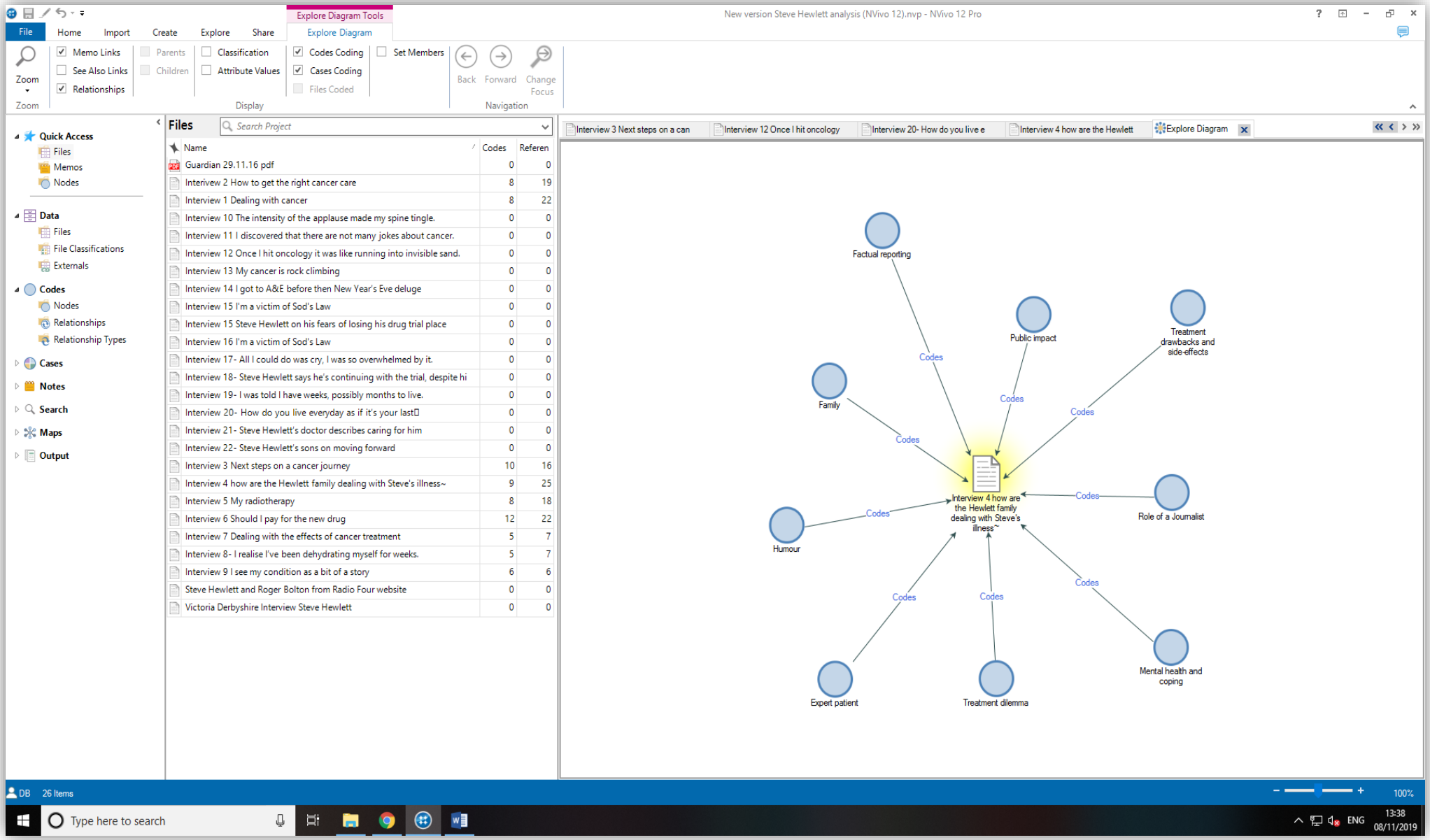
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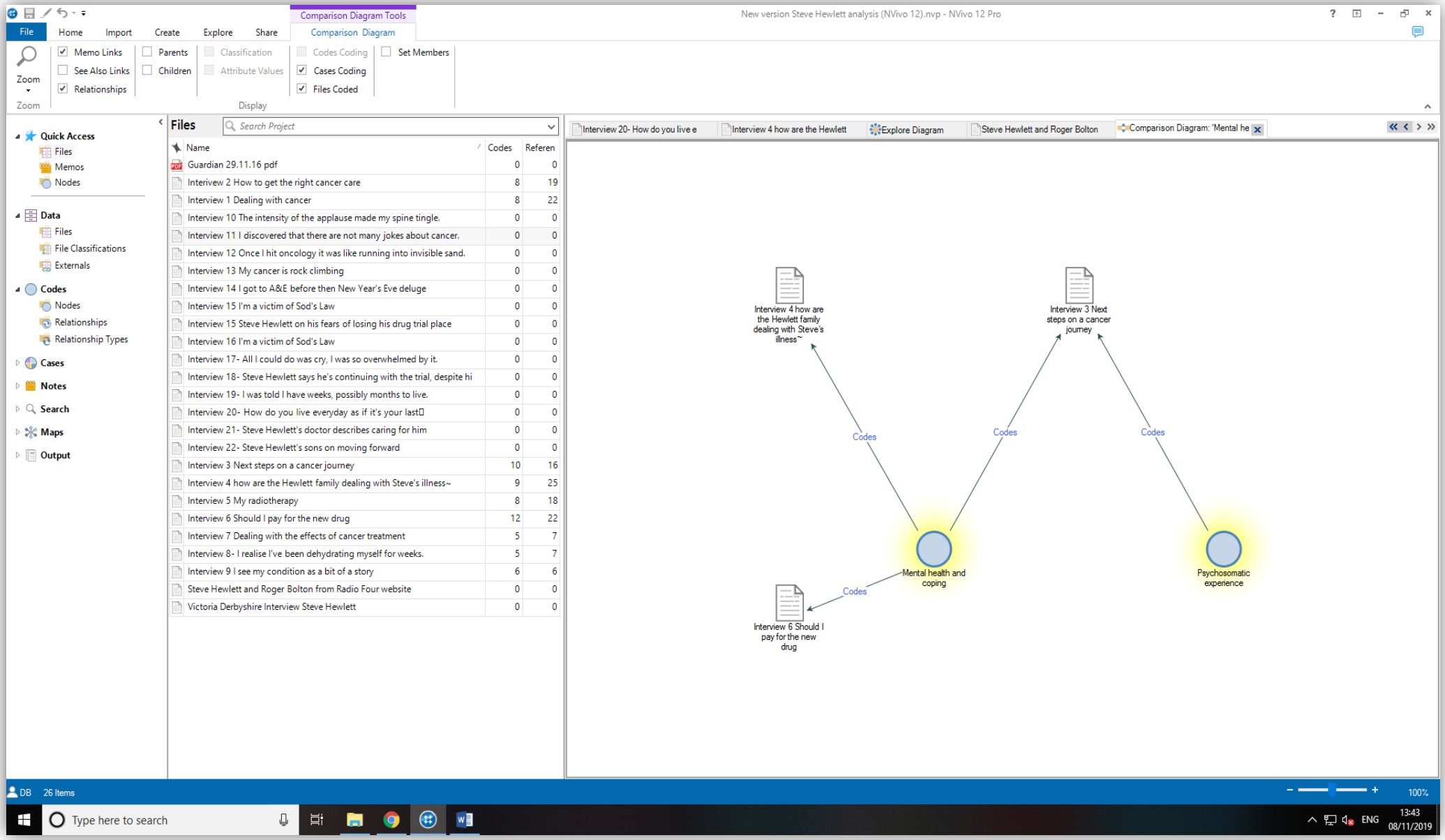
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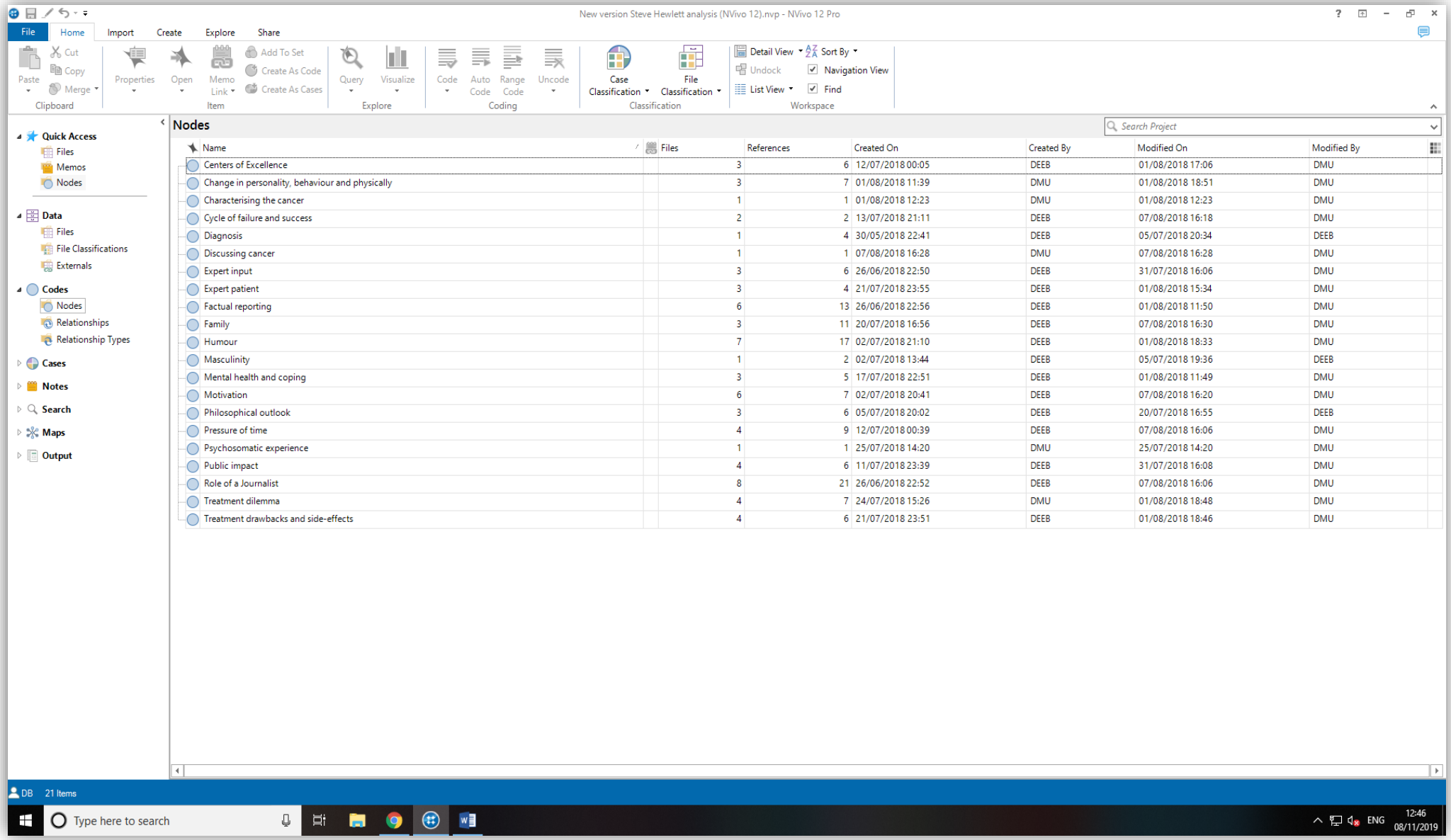
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Public impact 4 6 11/07/2018 23:39 DEEB 31/07/2018 16:08 DMU
Role of a Journalist 8 21 26/06/2018 22:52 DEEB 07/08/2018 16:06 DMU
Treatment dilemma 4 7 24/07/2018 15:26 DMU 01/08/2018 18:48 DMU
Treatment drawbacks and side-effects 4 6 21/07/2018 23:51 DEEB 01/08/2018 18:46 DMU
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Appendix 9

From: HLS Faculty Research Ethics Committee <hlsfro@dmu.ac.uk>
Sent: 16 March 2018 09:01
To: Dee Bij
Cc: Kay De Vries; HLS Faculty Research Ethics Committee
Subject: FREC: Confirmation of no ethical issues - (Ref. 3057)

Dear Dee

RE: Confirmation of no ethical issues – Project Title: One man's journey with advanced oesophageal cancer and documentation of those experiences via the media, Steve Hewlett: A case study (Ref: 3057)

We are writing to confirm that the Chair of the Faculty Research Ethics Committee has advised that the above named project does not require ethical review.

This will be reported in the next Faculty Research Ethics Committee meeting.

Message sent on behalf of the Ethics Chair

Regards

Faculty Research Ethics Committee

Faculty of Health & Life Sciences, De Montfort University

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Website / forms: http://www.dmu.ac.uk/research/ethics-and-governance/faculty-specific-procedures/health-and-life-sciences-ethics-procedures.aspx